DOCUMENT RESUME

ED 224 872 CE 034 293

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TITLE Humanistic Patient Care Training: Content and Methodology. Interdisciplinary Team Training and Humanistic Patient Care for Hospices. Monograph 5.
INSTITUTION ELM Inst., Rockville, MD.
SPONS AGENCY Health Resources Administration (DHHS/PHS), Hyattsville, Md. Div. of Associated Health Professions.
PUB DATE Sep 81
CONTRACT HRA-232-79-0082
NOTE 231p.; For related documents, see CE 034 290-292 and CE 035 384.
PUB TYPE Guides - Classroom Use - Guides (For Teachers) (052)

EDRS PRICE MF01/PC10 Plus Postage.
DESCRIPTORS Allied Health Occupations Education; Communication Skills; Course Content; Health Facilities; *Health Personnel; Health Services; *Humanism; Humanistic Education; Interdisciplinary Approach; Leaders; Medical Education; *Medical Services; Nursing Homes; Patients; Professional Development; Residential Care; *Staff Development; Teaching Guides; *Team Training; Values
IDENTIFIERS *Hospices; *Humanistic Patient Care; Interdisciplinary Health Teams; Monitoring; Process Skills; Terminal Illness

ABSTRACT

This monograph, the fifth in a series of five, provides training information for hospice staff in improving interdisciplinary team functions and humanistic care provisions. Its purpose is to provide a skilled group trainer with the hospice-specific insights necessary to conduct training in humanistic patient care. Chapter 1 covers training program content and structure, trainer roles, and preparation for training. In chapter 2 are vignettes that explore contrasting and conflicting examples of patient and staff values and attitudes as they may occur within the 11 content areas in humanistic care training. Chapter 3 contains vignettes that provide examples of staff use of process skills in the provision of humanistic patient care. Chapter 4 offers guidelines for training in four categories: humanistic patient care definitions, components, and applications; psychosocial variables in working with dying patients; patient and family needs, environment, and rights; communication skills and styles; and monitoring of humanistic patient care provisions. Each section has this format: background information for trainers, training session outlines, examples from hospice training experiences, and selected resource materials. Following a bibliography are definitions and tables of contents of the five monographs. (YLB)

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HUMANISTIC PATIENT CARE TRAINING: CONTENT AND METHODOLOGY

Monograph 3 in a Series:

INTERDISCIPLINARY TEAM TRAINING AND HUMANISTIC PATIENT CARE FOR HOSPICES

September 1981

Developed under
Health Resources Administration
Contract No. 232-79-0082
U.S. Department of Health and Human Services
Public Health Service

CE034 293

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DOC 2

HUMANISTIC PATIENT CARE TRAINING:
CONTENT AND METHODOLOGY

Monograph 5

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Developed under
Health Resources Administration
U.S. Department of Health and Human Services
Public Health Service

An ELM Institute Project:

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September 1981

MONOGRAPH 5

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FOREWORD

The ELM Institute is a not for profit corporation, founded to conduct research and education in established and emerging areas of health care delivery and policy. From the outset, one of the Institute's three major areas of interest has been terminal care, the others being cancer care and long term care of the impaired elderly.

While terminal care must function in the established health care delivery arena, its goals are substantially different. Instead of cure and rehabilitation, it acknowledges death and seeks to assure physical, spiritual, emotional and social comfort. We reasoned that this type of dichotomy would present organizational, structural, economic, and personnel difficulties as these two approaches were merged. These issues and their management are primary areas of interest to Institute staff.

For these reasons the Institute was pleased to receive the DHHS award to study the interdisciplinary team training and humanistic care training needs of terminal care programs. I believe the results contained in these volumes confirm our mutual judgment that alternative modes of health care delivery require unique staff interactions and support mechanisms in order to survive and meld with the current care system. Further, I believe you will find that the concepts utilized in this model for training and team development have broader programmatic applications than terminal care.

The Institute will continue to test and refine the model, and is willing to work with those programs who require specialized expertise or who face unique circumstances. In many other cases, it is our hope that these modules will provide sufficient information to an informed and experienced process consultant.

From the Institute's perspective, we intend to continue similiar research and development projects in health care delivery and in policy formulation. We are pleased to have had an excellent opportunity to further our investigations and to work with an excellent group of advisors and collaborators.

Lee E. Mortenson
President
ELM Institute
Rockville, Maryland
August, 1981

PREFACE

Purpose of the Series

The purpose of this series of monographs is to assist hospices in improving their quality of care, through enabling them to improve their ability to meet the needs of their patients and families. Objectives include: improving the functioning of the interdisciplinary team, integrating the patient and family into the team, ensuring the appropriate utilization of professional services, and improving staff awareness and capability of providing humanistic patient care. These objectives may be attained through a training program for hospice staff described in the monographs.

The goals and objectives of the training program relate directly to those of hospices. Both direct attention to the whole person - patient, family member, or staff member - individually and as a group member. Both attempt to integrate the physical, psychosocial and spiritual approaches to care. Both combine scientific knowledge, skills, affective awareness, and interdependent coordination of activity to achieve an orientation to comfort and growth for all those involved. Hospices, having already made significant progress toward their goals, can expect the training program to enable them to approach these goals more quickly, more comfortably, and more effectively.

Hospice staff members need to be highly skilled in both the technical and the humanistic aspects of health care. These monographs acknowledge the need for high quality professional skill on the part of all staff members but do not address it. Training information in this aspect is assumed to be already in place. This series of monographs was developed to fill an acknowledged gap in training information for hospices, that is, training information in improving team function and humanistic care provision.

The monographs provide a significant contribution to these hospice activities. They provide factual information, approaches, and methods for qualified trainers to utilize their existing knowledge and skills successfully in the unique environment of the North American hospice. The series is intended primarily for the use of trainers assisting hospices, and not as a self-

help guide for hospices; however, all or parts of the series may be a helpful resource not only to hospices and hospice trainers but also to others concerned with the interdisciplinary and humanistic qualities of hospice care.

These monographs are working documents. The information they provide has been developed by trainers who are leaders in the field, tested in two demonstration hospices, and then modified on the basis of these tests. The developers anticipate that additions and variations will be appropriate over time and through continuing use of the document.*

Review of the Series

This series of five monographs was written by the ELM Institute under the general title: Interdisciplinary Team Training and Humanistic Patient Care for Hospices. The monographs, outlined below, address the following topics:

Monograph 1:	Guide for Hospices
Monograph 2:	Guide for Trainers
Monograph 3:	Training Program Design
Monograph 4:	Interdisciplinary Team Training: Content and Methodology
Monograph 5:	Humanistic Patient Care Training: Content and Methodology

Monograph 1, Guide for Hospices, is directed to hospice administrators. It may, however, be of interest to trainers and others. It describes teams, team function and the provision of humanistic patient care, and assists hospices to determine whether or not they have reached the state of development needed for this training. It identifies the objectives of the training and the anticipated benefits to the hospice, as well as the role of the hospice administration in the training and its financial and other obligations. In particular, it assists hospices to recruit and select one or more qualified trainers from outside the hospice organization to conduct the training. It also supplies useful suggestions to hospices based on ELM's hospice training experience.

Monograph 2, Guide for Trainers, is directed to "outside" trainers who may be invited by a hospice to conduct its training, although

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* Reports of experiences with the monographs and any recommended additions or modifications to them would be welcomed by the developers - the ELM Institute, 11600 Nebel St., Rockville, Maryland, 20852 - for inclusion in future revised editions.

it may be of interest to others, as well. It is recommended that all trainers anticipating work in hospices read this monograph, regardless of their prior experience, in order to learn more about the unique features of a hospice and the implications of training in the hospice setting. The document provides background information about the hospice concept, models, components, standards, and staff characteristics. It also assists trainers to determine whether or not the hospice and the trainer match sufficiently well for the training to be successful, and to recommend the appropriate staff members to be trained. The role of the trainer is reviewed and suggestions from ELM's hospice training experience are offered.

Monograph 3, Training Program Design, is directed primarily to the trainer(s) who has contracted with the hospice to conduct the training. It will also be useful to hospices in working with the trainer in developing their programs. It may also be of value to others. The monograph provides a detailed statement of goals and objectives of the training, and describes the steps of the training design: orientation of staff, initial data collection, identification of issues specific to the hospice concerned, preparation of reports, feedback of the reports to the staff, confirmation and prioritization of issues, and joint staff/trainer selection, design and planning of a customized training program to address these issues. Again, examples from hospice training experience are reported.

Monograph 4, Interdisciplinary Team Training: Content and Methodology, is again directed to the trainer, although it may also be of interest to hospices and others. It contains the materials needed to conduct the training, and includes examples of issues and approaches to interdisciplinary team training in the hospice setting. It is not intended to limit the trainer but to assist by providing hospice information, outlines of successful training sessions, examples from hospice training experience, and relevant literature resources. It contains checklists and hints that may be useful to trainers, particularly in their first hospice training experiences. The monograph is divided into four sections, covering the major interdisciplinary team training categories: goals, roles, structure, and procedures.

Monograph 5, Humanistic Patient Care Training: Content and Methodology, provides trainers with information concerning humanistic patient care training in hospices and is similar in structure to that in Monograph 4. Again, although directed to the trainer, it may also contribute to understanding by hospices and others of the humanistic approach and what training in humanistic patient care entails. The document provides examples from hospice experience in humanistic values and orientations, in issues relevant to training, and in humanistic training in hospices. There are sections on background information, checklists and hints for trainers, and outlines of successful training sessions. Pertinent references to the literature are included. The monograph addresses the definition of humanistic patient care and the topics: psychosocial variables in working with dying patients; patient and family needs, environment and

rights; patient/staff relationships, including listening and stress management techniques; staff/staff relationships and staff relationships with other health professionals, including listening and communication skills; and monitoring of humanistic patient care provision.

It is not essential for hospices or trainers to acquire the complete series. Each monograph was prepared to address a different audience and to be complete in itself. This approach however, necessitated the inclusion in more than one monograph of certain sections common to more than one audience or title. The reader of the entire series will be well aware of these repetitions.

Review of the Project

This series of monographs was developed by the ELM Institute under a two-year contract with Health Resources Administration, Department of Health and Human Services, entitled: "Assessment of Staffing Patterns and Development of Interdisciplinary Team Training and Humanistic Patient Care in Hospices". The contractor was the ELM Institute, with David J. English, D.B.A., its Executive Director, the project director and Dottie C. Wilson, its Hospice Group Director, the associate project director.

A Panel of Consultants was named to provide technical assistance and to assist in the development of a training program plan and an evaluation plan. Some members of the panel conducted hospice training sessions. An Ad Hoc Review Committee was named, representing major health care associations and approaches, to provide a broad perspective to the work undertaken and to assess its applicability to the health care system.

An analysis was performed of documents describing the organization and staffing patterns, including staff characteristics, in current U.S. hospices. The documents analyzed were the more than 250 applications by hospices to the Health Care Financing Administration for waivers of certain reimbursement regulations. This analysis, along with bibliographies and assessments of the anticipated impact of training on hospices, was published in July 1980 in a report entitled: An Assessment of the Existing Staffing Patterns and Personnel Required in a Hospice to Deliver Interdisciplinary Patient Care and the Problems Related to Delivering Humanistic Care to Hospice Patients.

ELM staff and Panel of Consultant members developed a training program plan, a statement of training goals and objectives, and, with the subcontractor, an evaluation plan. To test the plan, training was conducted in two demonstration hospices,

one an independent home care program and the other an inpatient and home care program within a hospital. The training was conducted by certain members of the panel of consultants with ELM coordination. Those trained included steering committees, a management team and patient care teams. The training was evaluated by the ELM Institute's subcontractor, Perry Cohen Associates, using both impact and process evaluation techniques.

Acknowledgements

The smooth conduct of the HRA contract and the significance of its results have been made possible by the availability and assistance of the HRA Project Officer, Mr. Thomas Aschenbrener. ELM appreciates very much his contribution to the success of the project and to the series of monographs.

All those who contributed to the prcject and to the series of monographs are listed in the Appendix to this volume. ELM extends sincere thanks to each of them, and in particular acknowledges the significant contributions of John A. Hackley, M.S.W., Mark S. Plovnick, Ph.D., Charles Seashore, Ph.D., and Terence F. VanOrshoven, Ph.D., to the development of the monographs.

The success of the training program demonstrations was in large part due to the enthusiasm, cooperation and support of the leadership of the two hospices concerned. Special thanks are due to Anne Kirschner Katterhagen, R.N., B.S.N., Executive Director of Hospice of Tacoma, Tacoma, Washington, and both Maryanne Fello, R.N., Director of Hospice Care, and Madalon Amenta, Dr.P.H., Director of Research and Education, Forbes Hospice, Pittsburgh, Pennsylvania, for their interest and assistance in the training demonstrations.

The ELM staff, including senior associates, research associates, and support staff, have been most helpful throughout the project and monograph preparation. We appreciate it.

David J. English, D.B.A., Project Director, and Dottie C. Wilson, Associate Project Director.

September 1981

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CHAPTER I. INTRODUCTION TO HUMANISTIC PATIENT CARE TRAINING

A. PURPOSE OF THE MONOGRAPH

It is the purpose of this monograph to provide a skilled group trainer with the hospice-specific insights necessary to conduct training in humanistic patient care. It is also intended to document what experience there has been in training hospice staff. Though the materials found in this monograph are not intended to offer step-by-step instruction to those trainers possessing little relevant experience, training session outlines and significant content guidance have been provided for those trainers possessing the necessary process skills in working with human service groups. It is intended that these materials, when coupled with a trainer's personal knowledge, skills, and experience represent a comprehensive package enabling the conduct of a mutually rewarding and successful training program in humanistic patient care for both trainer and participants.

The commitment to begin training in humanistic patient care is not one which should be taken lightly for it entails far more than the "freeing up" of staff time to participate in the initial training sessions proposed in this training. These materials represent only a beginning. As training concerns values, attitudes, beliefs, relationships and skills, it is realistic to assume that training will cover a considerable period of time for it to have a major impact on team effectiveness and the patterns of care delivery. As in all staff development efforts, the process is ongoing and evolving. Issues examined today become the foundation of explorations to be made tomorrow. The participants of today's training are changing, viable, growing organisms with changing needs, new awarenesses, and new contributions to share with others. Hospices should be advised by trainers, therefore, that there is a pronounced need to continually monitor, constantly examine, and forever observe the effectiveness and the humanness of the care being provided in the hospice environment. This continual evaluative, or reassessment process will enable individuals who have gone through this initial training to examine their own behavior while caring for dying individuals and their families. Further,

future training designed to explore the continued individual developmental efforts in the achievement of a more humanistic approach to care of the dying supports the assimilation of new care providers who did not participate in original training activities, while also reinforcing the training received by those who did participate. Chapter IV, Section D of this monograph deals with specific monitoring activities and renewal exercises for humanistic patient care training. The trainer must demonstrate responsibility in conveying the information to hospice administrations.

These materials assume a premise that in order to bring about a more humanistic approach to caring for the dying, it must first be conceded that health care as a practice does not exist apart from providers of that care. Health care as a continuing process presents opportunities for people to be of service to other people in times of stress and sadness and crisis. All health care providers have an opportunity to draw upon their own resources- medical skills and techniques, past experiences with particular disease processes, interpersonal skills, and their own humanness in providing this service. It is the combination of all of these resources which shape a care plan; but it is the latter two attributes which influence the approach to the provision of the care.

The growing interest of late in humanistic medicine, and its eventual operationalization to humanistic patient care, suggests an increased awareness of the patient as more than an individual with a disease, emphasizing a colleagueal relationship between patient and care provider. The development of such a colleagueal relationship is hampered, however, if there is little regard for the value of the care provider; each provider must maintain a personal sense of well being for himself as well as for his fellow team members. Only when the human resources of both the patient and the care provider are valued can humanistic patient care be attained in a manner which supports the care provider, enabling return to the continual task of providing sensitive, humane care to patients day after day.

Health professionals, allied health professionals, and their health administration associates have sought to identify those personal attributes and environmental conditions which influence the achievement of this delicate balance of sensitivities between care provider and patient. Based on the works of some of these individuals, the materials provided in this monograph offer a guide to exploring those content and skill areas which, when learned, bring about an increased awareness of needs of both fellow care providers and the patient/family.

B. TRAINING PROGRAM CONTENT AND STRUCTURE

The effectiveness of training in humanistic patient care may be greatly enhanced by a previous examination and processing of those organizational and team issues which relate to goals, roles, structure and procedures as dealt with in Monograph 4. By working through team building activities first, the group is frequently able to divest itself of standing conflict while learning constructive means of communicating differences. Once this has been achieved the group is better able to move beyond the organizational issues to other environmental issues, such as feelings on the team, which in part explain an individual team member's behavior and his approach to patient care. When a sense of trust has been developed, further communication and sharing are encouraged, both of which are vital to the effectiveness of the humanistic patient care training process and the growth experience.

Hospice in its true sense is vastly different from conventionally practiced health care. When it has been determined that hospice care is appropriate the whole approach to care shifts emphasis. This facet in and of itself has the potential for creating great conflict within, among, or between hospice staff and patients/families. The highly individualized care approach of hospice necessitates the presence of a highly skilled, sensitive, efficiently operating team which is responsive to physical discomfort, psychological distress and emotional disequilibrium. It is the intent of training in humanistic patient care to further the team in its transition to this optimal position of functioning and effectiveness.

An adaptation of the humanistic patient care definition as it relates to hospice care is helpful in providing a greater understanding of the content of these training materials.

Humanistic Hospice Patient Care is the provision of hospice services with special attention to:

- The effective and affective relationships between hospice staff and patients and families,
- The quality of the personal interaction between hospice staff and patients,
- The necessary and desired psychosocial and spiritual support of patients, families, and staff, and
- The motivation of patient and family to behavior that ameliorates illness or promotes well being.

Hospice acknowledges that dying is a human event, profoundly influenced by the background, lifestyle and temperament of the person dying. Hospice implies the involvement of staff as persons

"content areas" identified for training in humanistic patient care:

- Patient/Family Interactions
- Psychosocial Aspects of Aging
- Psychosocial Aspects of Illness
- Psychosocial Aspects of Dying
- Psychosocial Implications of Cultural Background
- Psychosocial Implications of Spiritual Background
- Patient Care Environment
- Maintenance of Patient Independence
- Patient Rights
- Assessments of Patient/Family Needs
- Work Environment of Staff

Through the use of vignettes, Chapter II, humanistic values and orientations in hospice illustrates the influence that each of these topics has on the quality of care provided through the hospice experience.

Demonstrating an understanding of the multi-faceted nature of each patient/family relies, in part, on staff's willingness and ability to examine intrapersonal and interpersonal feelings, attitudes and behavior. The intra- and inter-personal processes required to encourage the provision of humanistic patient care are the issues explored in Chapter III, illustrations of hospice issues. Seven process issues have been identified:

- Intrapersonal Awareness
- Interpersonal Awareness
- Listening
- Communication
- Learning/Teaching
- Stress Management
- Management/Supervision

The process of facilitating the exploration of intrapersonal and interpersonal issues is developmental and as outlined in these materials sets the stage for skill learning and building.

Chapter IV, approaches to training, represents the largest and most substantive chapter in this monograph. Ten training sessions presented under five broad training caregories are supported with background information for trainers, examples from hospice training experience, and selected resource materials. The eleven content areas identified in Chapter II and the seven process issues/skills examined in Chapter III are presented both didactically and experientially in training activities outlines in this chapter. The chapter is divided into five training categories:

- Humanistic Patient Care Definitions, Components and Applications
- Psychosocial Variables in Working with the Dying Patient
- Patient and Family Needs, Environment and Rights
- Communication Skills and Styles: Patient/Staff Relationships, Staff/Staff Relationships, and Other Health Professionals/Staff Relationships
- Monitoring of Humanistic Patient Care Provision

The approach taken in this monograph is derived from the ELM Institute's previous hospice experience, its experience from the Health Resources Administration training project, the experience of its trainers, and a review of the literature in hospice and humanistic medicine. The design of humanistic patient care training here reflects the demonstrated needs of operational hospices in this country. It is both anticipated and hoped, that use of these training materials over time in a variety of hospice settings will offer valuable modifications to its current design.

C. ROLE OF THE TRAINER

The focus of the training in humanistic patient care is to secure and improve upon the delivery of humanistic care in the hospice setting - a focus which is not to be confined exclusively to the membership of the interdisciplinary team. In hospice care the humanistic approach begins within each individual staff and volunteer and is conveyed to patient and family through sensitive interaction. Whether it is the receptionist answering the hospice phones, the nurse aide changing the bed, the volunteer relieving the family in the home to offer some respite, the music therapist providing therapeutic entertainment, or the administrator managing the fiscal concerns of the hospice, each contributes to the ambiance of the hospice environment. The network of care is, in fact, so interrelated that each individual within the network influences the behavior of others within the network. This ambiance is subtlely conveyed to the patient and family and is more specifically reflected in the attitudes and behaviors of all staff directly providing care to the patient and family.

It is not the intent of these materials, nor the focus of this training program to afford an opportunity for the in depth introspective exploration of values by participants. It is the mutual responsibility of the trainer and the contracting hospice to determine if the skills evident in the trainer are sufficient for the individual to assume the role of the trainer.

The trainer's role is to facilitate all humanistic patient care sessions in a task-oriented manner which:

- Create an environment of trust and sharing in which opportunities for growth are increased. and
- Raises appropriate issues/questions for participants which encourage their exploration of values,
- Prevents group movement into highly sensitive intrapersonal and interpersonal areas which may result in psychological/emotional damage to individuals.

Specific responsibilities of the trainer include:

- Familiarizing self with training materials and being minimally knowledgeable about the hospice staff,
- Preparing for each training session through the use of these and other materials,
- Providing substantive information in the identified "knowledge areas" OR making arrangement with the alternate trainer to do so, and

- Acting as the responsible resource person for key questions which cannot be answered in sessions.

It expressly is not the role of the trainer to provide therapy or facilitate a sensitivity group. Such exploration of highly sensitive areas could result in dysfunction of an individual or the team. While the exploration of personal values is a necessary preamble to humanistic patient care training, the emphasis is greater in the area of assisting staff to deal effectively and affectively with others when values are in conflict. A primary goal of training is staff's ability to become non-judgmental, while maintaining personal integrity.

Guidelines have previously been identified (Monograph 1, Chapter III) to assist hospices in the selection of appropriate trainers. Monograph 3, Chapter IV, provides additional information about principal and alternate trainer selection. In particular, the guidelines in the chapter should be reviewed as they relate respective trainer responsibilities of "principals" and "alternates".

D. PREPARATION FOR TRAINING

How arrangements proceed in the final preparation for humanistic patient care training may be indicative of how the training program is viewed by the sponsoring organization or the hospice. Is the training, in fact, regarded as a "fringe"? If this is the sentiment of the host organization, preparation for training begins with the trainer attempting to alter this impression with both administration and hospice staff. Humanistic patient care training is not to be viewed as a fringe, but rather as an essential to the effectiveness and efficiency of the hospice in providing higher quality, more sensitive care.

The trainer and the hospice director should negotiate a mutual agreement about the following in regard to time, participants and place.

- Time - Sufficient time is to be available for each session to enable participants to explore their own internal values in regard to the content area pursued in that session. It is not intended that this value sort would require deep exposure, but rather would entail the emergence of appropriate questions for some degree of introspection. Though topic areas have been outlined for a format of approximately three hours each, on some occasions hospices may combine or delete topics. Regardless of final format, each session should be convened for a minimum of two hours to facilitate the sharing and learning process.

- Participants - Each participant is to be advised in advance of his/her responsibilities as a member of the training group (e.g. promptness, confidentiality). An awareness of the intrapersonal and interpersonal nature of the training should be explained to participants in sufficient depth that they may make their own choice about participating (e.g. no persons experiencing major emotional transitions should be participating). Training effectiveness will be hampered if persons are present who have been given no option to attend or not to attend so participants are to have at least minimally volunteered.

- Place - The place selected for training also speaks to the importance of training. Continuity and flow of process occurs when participants are in comfortable surroundings and are uninterrupted for the duration of the sessions. Environmental expectations must be flexible based upon what the hospice can offer, however, the important element

is the location's non-permeability - no ringing phones are to be in the room and only absolutely essential interruptions are to be tolerated. The hospice administration should be well aware of the trainer expectations in this regard.

It is recommended that the trainer prepare a checklist of details to be finalized, after absorbing the information contained in the rest of this monograph. The checklist should be in two parts, one for the opening session, and the other for all sessions. Exhibit 1 following highlights some of the items to be considered.

Exhibit 1

Trainer Preparation Checklist

First Session

___ Location identified and secured.

___ Dates and times for all training sessions confirmed and scheduled.

___ Participants identified and confirmed for continuing involvement in training.

___ Trainer knowledgeable about constellation of group (i.e. ratio of supervisory staff to general staff, interpersonal pressure points, coalitions).

___ Description of trainer's role as facilitator within the training process prepared for presentation to the group in the first session (may need to be continually reiterated to ensure group "owns" the sessions).

___ Description of intent of training provided including statement of the voluntary nature of participation.

___ List of participant responsibilities prepared and duplicated (if to be used).

All Sessions

___ Relevant monograph materials reviewed prior to each session.

___ Additional resource persons (alternate trainers) identified, confirmed with hospice and secured for necessary dates.

___ Audiovisual and/or special equipment or supplies requested well in advance (confirm availability day before related training session).

___ Handouts (to include assignments and exercises) prepared and duplicated.

___ Icebreaker exercise prepared in the event required (to be determined based on whether group is principally the same group which received interdisciplinary team training and the timing of training in relation to previous training).

CHAPTER II. EXAMPLES OF CONTENT IN HUMANISTIC VALUES AND ORIENTATIONS IN HOSPICE

An examination of humanistic values and orientations in hospice care is one critical focus of these training materials. Values, of course, are an integral part of each person and enter into all aspects of patient care and all aspects of training in humanistic patient care. Values are "formally" addressed in training in the opening sessions on humanistic patient care components and definitions.

Recalling the eleven content areas previously identified, vignette examples* (Exhibits 2-34) are provided in this chapter which explore the following:

A. Patient/Family Interactions
B. Psychosocial Aspects of Aging
C. Psychosocial Aspects of Illness
D. Psychosocial Aspects of Dying
E. Psychosocial Implications of Cultural Background
F. Psychosocial Implications of Spiritual Background
G. Patient Care Environment
H. Maintenance of Patient Independence
I. Patients' Rights
J. Assessment of Patient/Family Needs
K. Work Environment of Staff

Focusing upon these eleven content areas, contrasting and conflicting examples of how humanistic patient care is "operationalized" by hospice staff is explored. Given differences in personal values, patient care which may be perceived to be "humanistic" by one care provider may be interpreted as not so humanistic by the receiver of that care. Response patterns will vary between staff members for the same presenting need or problem. Those staff persons more knowledgeable about the patient's background, belief structure, fears and hopes will be more accurate in their assessment of needs and more sensitive in their response to those needs.

The vignettes appearing in Chapters II and III lend themselves nicely to utilization as teaching tools by either the humanistic patient care trainer during "formal" training activities, or by staff as they conduct ongoing monitoring activities. Group discussions about the vignettes may be most meaningful when the focus (for facilitation) is on process issues/skills.

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* The ELM Institute wishes to express special appreciation to Mr. John A. Hackley who contributed vignettes (Exhibits) appearing in this chapter. All vignettes reflect actual hospice experiences.

A. EXAMPLES OF PATIENT/FAMILY INTERACTIONS

Exhibit 2

A fifty-four year old attractive woman was discovered to have an advanced stage of breast cancer, and had a radical mastectomy nine months ago. Initially upon discharge from the hospital she was visited by a representative of a community volunteer group of women who offered supportive counseling for mastectomy patients. Soon after surgery she obtained a prothesis but was having significant difficulty in adjusting to her loss though her husband of thirty-one years had been, and was continuing to be, immensely supportive. Several weeks ago the woman was referred to a hospice home care program. The social worker was one of the first team members to visit the woman as she had been reported to be "highly distressed" by the home care nurse. Since her surgery the woman had not permitted her husband to view fully the scarred area of her body. In her rapidly deteriorating physical condition she was increasingly dependent upon him for much of her personal care needs which was a source of great humiliation for her. The barrier grew and the wife became unable to speak honestly with her husband about her personal distaste for, and her projected fears about his distaste for, the disfigurement caused by her cancer. Through working with the patient, the hospice social worker became aware of these feelings and provided an opportunity (through role playing), for the patient to "rehearse" sensitive discussions which would later be held with the husband.

Exhibit 3

A middle-aged patient being maintained at home exercises a regimen which has successfully managed the distressing symptoms of his progressing disease. The man's wife is pleased to have him back in the home and has been his devoted care giver from the start. The patient's two adult sons have elected to drop out of their respective schools for the term and return to the community to be closer to their father during his final weeks. The sons elect to get day jobs and cooperatively rent a small apartment near their parents' home - thus affording their parents the needed privacy while still being close at hand. The sons have complained to the home care nurse that under their father's current regimen he remains most alert during the day time when few family members are in the home, and grows weary in the evenings - just when they're available to be with him. In response to the family complaint a new drug regimen is implemented which leaves the patient very alert in the evenings, and in fact, also long into the night after everyone else has gone to bed, leaving the patient awake and alone.

Exhibit 4

A highly frantic and devoted husband of a thirty-four year old attractive woman has requested an immediate appointment with the hospice social worker. His wife of three years has, in the past nineteen months, undergone a series of operations for cancer. Her prognosis for survival is not good, six to nine months. Though not an active home care patient at the current time the appropriate admission processing at hospice has been completed and when the home care services are required she would become an active home care patient by her and her husband's mutual choice. Since her most recent discharge, however, the young woman has been very depressed about the disfigurement from her surgery and her impending "drawn out" death. One evening she announced to her husband that she was "offering him an out". She tearfully described herself as "useless" to him and announced she had contacted her parents who resided in a city some 1,100 miles away and they had agreed that she come live with them "for however long she had left". The husband could not reason with his wife and convey to her just how important it was that he be with her for these final months - there was so much left undone, so much left unsaid. He needed her for these last few months. Teary-eyed and frot with combined resentment, anger, and love for his wife, he pleaded with the hospice social worker to intervene.

B. EXAMPLES OF PSYCHOSOCIAL ASPECTS OF AGING

Exhibit 5

An elderly man who is a hospice inpatient is visited daily by his devoted wife of 56 years. The couple is a favorite of hospice staff because of the great affection demonstrated for one another (hand holding, quiet talks, "hello" and "goodbye" kisses). In a gesture intended to "rise above stereotypes" several of the staff make arrangements to have the man transferred to a private room with a double bed in order to afford opportunity for greater intimacy. The couple is outwardly embarrassed by the frankness and suggestiveness of the move.

Exhibit 6

A hospice patient, a sixty-eight year old widowed female, is supported in the home of her middle-aged niece. The elderly woman had been exhibiting despondent and anxious behavior for some months prior to her diagnosis and this behavior ultimately prompted the niece to bring the woman to see a physician. Without knowing much about the patient's history, yet in an effort to allay the concerns of the niece, hospice staff speak of the sensitivity of dying patients, knowing of their fate long before an official prognosis has been made, and concluding that the patient is adapting to the knowledge of impending death. After several weeks of hospice staff engaging in carefully selected conversations about dying and providing opportunities for sharing on the elderly woman's part, a nurse aide on evening shift learns, through careful listening, of the woman's inability to cope with the multiple losses in her last three years and sad about how "old" she feels.

Exhibit 7

A seventy-four year old single woman is terminally ill with an inoperable malignant tumor in the lower abdomen. Her symptoms are controlled and she is able to live independently at home alone except for scheduled visits of a home care nurse for medication injections. Although she requires considerable rest each day, she can go out at will and participate in customary social activities of her choice. However, her "friends" continually borrow her automobile under one pretext or another because they believe she is too old and frail to drive alone. Because of this resulting unnecessary restriction of her mobility, she becomes virtually homebound because she resents being dependent upon others for transportation.

C. EXAMPLES OF PSYCHOSOCIAL ASPECTS OF ILLNESS

Exhibit 8

One nurse continually makes a distinction between the "sick" role and the "dying" role and discusses in patient care meetings the different needs that patients and families have given these distinctions. Her approach to providing care is one which she views as humanistic because the patient is "in control" and the family is the "caregiver". Family members, however, feeling insecure and at a loss as to what to do, are indignant that the nurse has left so much responsibility for the care of the patient on their shoulders.

Exhibit 9

After repeated visits to the home of an elderly woman cared for by her husband, nurses are distressed to learn that the woman is continually in pain and the husband has established his own schedule for administering medications despite the hospice's established regimen. Upon questioning the husband it is learned that he does not like following the regimen because it makes his wife dopey and thus he is unable to "force" her food; and, if she doesn't eat she won't get strong. He has been informed repeatedly in the past by physicians and nurses of the importance of his wife maintaining her strength to fight the cancer. The nurses are at a loss as to how to assist him in making the transition from caring for a sick person who will recover, to caring for a sick person who will die of the disease.

Exhibit 10

A fourteen year old boy is terminally ill at home receiving most of his care from his parents, his one older sibling and a few selected neighbors with some support and instruction from hospice home care staff. The patient falls in his home and sustains a simple fracture of the left femur. Hospice staff immediately recommend hospitalization for traction, positioning, skin care, etc. because it has been determined by the physician that death is too imminent to justify pinning or casting the broken leg. The family, which is secure and capable, disagree with the home care staff and insist there is nothing that would be done for the son in a hospital that the family cannot do with proper instruction and support from the hospice team.

D. EXAMPLES OF PSYCHOSOCIAL ASPECTS OF DYING

Exhibit 11

A fifty-seven year old man is within days of death because of the advanced stage of terminal illness. The care giving staff is satisfied with the completeness of the physical care being provided the patient. The niece and her husband, the only near relatives of the patient, are caring, devoted and very supportive of him. Although the patient seems to have achieved a wholesome level of tranquility and acceptance in most aspects of his coping with his illness, it is obvious to those closest that some unknown concern continues to trouble the patient exceedingly. The hospice social worker, after consulting with the patient, arranges a meeting in the home of the patient with the hospices interdenominational chaplain. Later, during his private discussion with the chaplain the patient admits he does not feel his "house is in order" because he seriously offended an old friend a few years ago; later the estranged friend died unexpectedly and the patient was never able to make his peace with him.

Exhibit 12

A forty-one year old single woman who has been living as a virtual recluse for almost ten years is found in her remote home severely ill of advanced cancer and practically comatose. She is immediately transferred to the inpatient unit of a hospice program. The patient responds well physically to the constant and extensive care received in the hospice unit and within two weeks is alert and outgoing. There is no indication that the progression of her terminal condition can be altered or repressed; however, her symptoms respond well to management regimes and her interest in her surroundings and those about her is very encouraging. A volunteer social worker insists to her that she must contact her estranged family because they have not known for many years where their daughter was living and they do not know that she is terminally ill; the social worker is convinced the patient will not attain final peace of mind without a reconciliation with her family. The patient refuses. Without the patient's knowledge the social worker telephones the family long distance and advises them of the whereabouts of the daughter and of the nearness of death because of her terminal condition. The family immediately telephones the daughter at the inpatient hospice unit but the patient will not accept the call.

Exhibit 13

An eighty-three year old woman near death has, for some time, been cared for in the inpatient hospice unit of a long term care facility administered by her niece. The patient has no other relatives in the city where she is now cared for and where she has lived for the past thirty-seven years. Her only immediate family is a sixty year old daughter who lives in Memphis, twelve-hundred miles away. The administrator, a cousin of the patient's daughter, has telephoned the daughter every few weeks to report to her the condition of her mother and the stages of her physical deterioration. At the times of these calls she has consistently encouraged the daughter to make a trip to visit. On each occasion the daughter has had one or another complex reasons for not being able to travel to her mother's bedside. At last when the physician and the hospice staff have agreed that death is very near at hand, the administrator telephones the daughter and insists that she come at once to see her mother - "otherwise you will always regret that you did not see her alive one last time".

E. EXAMPLES OF PSYCHOSOCIAL IMPLICATIONS OF CULTURAL BACKGROUND

Exhibit 14

A hospice located in a community with a large Italian population has served several patients from this tightly knit cultural community. Staff have become very familiar with some of the demonstrations of grief exhibited by this group. On more than one occasion bereaved family members upon leaving the deceased patient's room have thrown themselves upon the floor of the hospice unit with loud expressions of grief and open displays of anguish. Hospice staff have permitted this behavior recognizing its cultural importance in the bereavement process. The demonstrations are, however, acutely disturbing to some of the other patients and families within the environment.

Exhibit 15

A hospice physician and social worker had been working intensely for some time with a twenty-seven year old Puerto Rican lady in the hospice's home care program. Periodic physical assessments of the patient's progressive illness and intermittent diagnostic findings indicated that the patient should be experiencing an increasing frequency and intensity of pain. However, the young lady would not admit to any significant discomfort. The hospice physician sensed that it was not the true absence of pain but rather some deeply seated emotional restraint that prevented the patient from admitting to experiencing severe pain. The social worker, assisting in ferreting out the possible cause of the patient's unwillingness to acknowledge her discomfort, met with the director of religious education in the parish where the patient had been active all of her life. It was this individual who pointed out that it is considered shameful for a Puerto Rican patient to indulge in expressions of pain. The expression of discomfort is something that bothers the rest of the family who want to be as helpful as possible. In addition, there is fear that complaints about pain will lead to hospitalization and ultimately the patient will not be able to die at home.

Exhibit 16

Some years ago the terminally ill man in his mid-thirties who was the founder of the national movement, "Make Today Count", told a public audience the following story. He, his wife and three children lived in a nice home in an attractive middle-class suburb in a moderately sized community. They had many young couples of like age and socio-economic background in their suburban neighborhood as their frequent social companions. In the late spring one year the man had been diagnosed as terminally ill, and physicians advised him that he could expect to live approximately six to eight more months. About a month later, after his neighbors had become aware of his medical condition, he and his wife were attending a cookout with several other couples at a neighbor's home. The couples were having cocktails out-of-doors on the patio when the terminally ill man suddenly became aware that he had been served his cocktail in a plastic disposable glass while all of the other guests were served their beverages in crystal glasses.

F. EXAMPLES OF PSYCHOSOCIAL IMPLICATIONS OF SPIRITUAL BACKGROUND

Exhibit 17

A sixty-two year old registered nurse has practiced her profession of nursing for forty-one years in a limited assortment of traditional acute care settings. After a move to the Rocky Mountain area with her family she secures a position as a relief home care nurse with a newly developing hospice program. The first home care patient to whom she is assigned is a fifty-two year old male who has just been admitted to the hospice program because his rapidly advancing abdominal cancer is causing him a great deal of pain. He is reluctant to follow precisely the self-medication schedule that has been prescribed because he believes the Brompton mixture is called for too frequently and if he takes the pain medication as prescribed his body will become immune to its effects in the future when the pain becomes more severe and more difficult to control. Additionally, the patient has been raised in a family environment of a religious persuasion that teaches that pain is divinely assigned as partial recompense for an individual's sinful life. The home care nurse is of a similar religious background and also believes pain can be experienced as retribution for man's sinful nature. In every other respect the nurse provides nursing care as prescribed on her weekly home visits, but she supports the patient in his decision to self-administer pain medication only on those occasions when the pain becomes unbearable.

Exhibit 18

A terminally ill patient was admitted to the home care service of a hospice program several weeks after his condition had made him homebound - weeks during which his wife had given him increasing and devoted twenty-four-hour-a-day care. As the home care team began to work with this couple they became progressively more sensitive to the aura of despondency that characterized the relationship between husband and wife. On the occasion of one home care visit by the hospice nurse the wife took an opportunity to talk about how oppressive it was for her and her husband to prepare for his death; they would never have the expectation of a life after death nor the comfort of their possible reunion in an after life. Later the nurse asked a minister who was a hospice volunteer to talk with the couple. Unfortunately, the minister belonged to the same religious persuasion in which the wife had been raised in her early youth, and learning of this, the minister informed the couple that they had never been validly married, in his judgment, and that their past twenty-eight years together had been totally without redeeming virtue. Quite naturally the original despondency of couple was intensified.

Exhibit 19

A hospice program in a community in the Southwest had admitted a sixty-two year old Hopi Indian who was near death. She had been transferred directly to the inpatient hospice service from a nearby regional cancer center because her home and family were located on a remote reservation. The hospice social worker recognized the distress experienced by the patient because of her concern at being far from her tribe when she knew death was near. The social worker contacted a Native American mental health professional at the community mental health center for advice and counsel. This person explained that tribal affiliation is the Native American's most basic identification; tribal teachings and experiences determine to a great extent the values and life goals of the individual, including the meaning of death and customs surrounding the burial of the dead. Immediately thereafter, members of the Hopi tribe living in the area, were contacted. They spent periods of time each day with the patient in the hospice and the patient was assured that after her death she would be accompanied by these Hopi volunteers back to her home where the traditional customs surrounding the burial of the dead would be observed.

G. EXAMPLES OF PATIENT CARE ENVIRONMENT

Exhibit 20

A hospice patient being cared for in his home had several open lesions which required daily cleaning and proper dressings. The family was instructed in techniques for care of the lesions and thereafter only periodic visits to the home were made to check on the well being of the patient. With each successive visit, care providers were distressed to witness the unsanitary conditions in which the patient, apparently content, existed. On one particular visit a nurse learned, to her sheer horror, that the patient's lesions were infested with maggots. Above the strong protestations of patient and family, the nurse insisted upon the removal of the patient from the home and hospitalization for the treatment of the maggots. The patient was administered anesthesia while in the hospital and while the procedure was a success, the patient never fully regained awareness of his surroundings and died in the hopsital - confused.

Exhibit 21

An eighty-three year old lady was admitted directly to the inpatient unit of a hospice program from a long term care facility where she had lived for the past four months. The patient had only a single niece as family and the niece lived several hundred miles away. The patient had lived alone for many years in a small apartment complex a few miles away from the hospice. During her first weeks at hospice the lady was very cooperative and undemanding, however, she was also passive, withdrawn and disinterested in persons and activities around her; the same behavior she had exhibited in the long term care facility. The hospice staff noticed that a woman had visited the patient several evenings a week from the very start of the patient's stay at hospice. A hospice nurse stopped the visitor one evening to introduce herself and become acquainted. The nurse learned that the young woman was a school teacher who lived very near to the patient's apartment in the same complex, and that ever since the patient had become so ill that she had had to enter the long term care facility, she had cared for the patient's cat. Her constancy in visiting the patient was in part prompted by the patient's very touching need to have frequent reports about her treasured cat which she had not seen since becoming seriously ill. The nurse reported this conversation to the entire hospice team. The volunteer director was able to find a veterinarian who would donate a feline carrying case to the hospice. The visitor was then given the carrying case and encouraged to bring the cat with her on each succeeding visit. In a very short period of time the patient's attitude began to brighten and she became much more responsive and participated in the active social life of the hospice.

Exhibit 22

While in the end stages of his terminal illness a man is admitted to hospice, alert and cheerful. His symptoms are well under control but he is so weak he can no longer leave his bed. Toward the end of his first week in hospice a brightly colored, attractive announcement appears on his breakfast tray. A May Day party and musicale with refreshments will be held on the hospice patio that afternoon. Later, while he is being assisted with bathing, he and the nurse discuss the party planned for that afternoon. With mild regret the patient mentions that it is unfortunate he cannot attend the party because he cannot get out of bed. The nurse promptly reminds him that in hospice there are no rule books; anyone who wants to attend any activity is welcome and encouraged to participate no matter what kind of vehicles one may arrive in. Every activity and social function is held in an area of hospice that will accommodate wheelchairs, patient beds or any other manner of conveyance. The patient, with renewed interest, plans on attending the May Day celebration.

H. EXAMPLES OF MAINTENANCE OF PATIENT INDEPENDENCE

Exhibit 23

The husband of a recently diagnosed terminally ill woman visits hospice to learn if his wife might qualify for admission. He reports that his wife is semi-independent and that he has been able to provide for all of her needed care himself. However, her care needs, although not complex, are becoming more constant and he fears that the time he must be away from home because of his employment is too long a period of time for his wife to be left alone. He knows that his wife is still independent enough that she will violently oppose coming to hospice as an inpatient. The administrator points out that hospice is a multi-level care concept that is dedicated to maintaining a patient at home as long as possible. So long as the husband is able and willing to provide for his wife's needs during his non-working hours, his wife qualifies and is most welcome to enter the hospice program as a day care patient. She now comes to hospice each weekday morning with her husband on his way to the office and calls for her at the end of the afternoon on his way home again from work.

Exhibit 24

A seventy-four year old woman, terminally ill with an expected life expectancy of about six months, has symptoms which are reasonably controlled except for intermittent pain. An aggravating accompanying condition is the progression of an arthritic condition which is beginning to limit the patient's ability to ambulate and is also affecting her dexterity. Her family practice physician has been able to maintain her at home with the periodic help of the visiting nurse service and the patient's daughter. However, the daughter has just had a CVA with some residual paralysis and will not be able to continue as a caregiver. The hospice physician advises that the patient will be able to enter hospice as a home care patient, as home care nurses and home health aides will be able to provide the same care and supervision previously provided by the daughter. Additionally, the hospice physical therapist and occupational therapist will work with the patient in her home to help reverse some of the functional limitations the patient is beginning to evidence because of the arthritic condition.

Exhibit 25

A widowed lady of seventy-seven years who has been diagnosed as terminally ill lives alone in a one bedroom condominium apartment located on the second floor. The patient, who walks with the aid of a walker, is fearful of falling on the stairs and thus adding a fractured hip to her already serious physical condition. Additionally, the patient does not have an automobile and the apartment complex is several miles from shopping, clinics and the family physician's office. The lady is admitted to the hospice home care program which provides chore service and volunteeer transportation to shopping and the doctor's office. Additionally, the hospice staff locate two neighbors in the same apartment complex who are interested in, and qualify for, volunteer service. These two volunteers are trained by the hospice staff to be effective and resourceful friendly visitors who will aid in the prevention of social isolation for the patient.

I. EXAMPLES OF PATIENTS' RIGHTS

Exhibit 26

An elderly woman who has been in the hospice home care program for the past four and a half months trips while alone in her apartment, breaking her right arm in two places. She is hospitalized for casting of the fractures and for a short period of initial adjustment to the condition resulting from the accident. Her married daughter and her husband, who live in the same community, visit her each day in the hospital. Upon notification of her discharge, she calls her daughter's home and asks her daughter to come to the hospital to bring her home. At 1:00 p.m. her daughter arrives at the hospital accompanied by a woman in a nurse's uniform who the patient has never seen before. After the three women are in the automobile and have left the hospital parking lot, the daughter informs her mother that the nurse is on the staff of Sunnyside Convalescent Center, that while in the hospital her apartment has been given up, her household items put in storage, and arrangements made for her admission to the Convalescent Center, "for her own good", have been finalized.

Exhibit 27

A seventy-five year old widow has just been discharged home from the acute hospital where she was operated on for abdominal cancer. She was told that the surgery disclosed that there was no possibility of removing the malignancy and that it had become so generalized throughout her abdominal cavity that chemotherapy was not advised. Her family physician wanted to refer her to the local hospice program where she could receive home health care should it ever be necessary. All of the arrangements that were suggested were very acceptable to the patient and she was discharged home and into the hospice service. The patient had been back in her own home two days when she was visited by a group of men and women who were all strangers to her. They told her that they were from a community church a few blocks away and that her name had been given to them by a member of their congregation who lived a few doors away, a person the patient had heard of, but had never met. The neighbor had heard of her terminal illness through neighborhood gossip and had reported to the group that she had never seen the patient go out to any Sunday church service in the past seventeen or eighteen years. The group told the patient they had come to her to give testimony to the goodness of the Great Spirit and to help her repent and seek forgiveness so she could be saved before her malignancy ended in death.

Exhibit 28

A widower with an irreversible terminal condition has for the past few months been in the home care service of his community's hospice program. Now he is in the inpatient hospice program because of the severe progression of his terminal condition. About two weeks before his anticipated death his adult son from the Pacific coast and his married daughter from New England both fly into town to visit him. Neither of them are sympathetic with the hospice philosophy and together they try to encourage him to be transferred to a medical center where a complete array of life extending measures are available. The elderly gentleman at last tells his concerned children that he is physically comfortable, surrounded by other patients and staff who care for him, and for whom he in turn cares deeply. He states that his "house is in order" and that his mind is at peace. He has no anxious desire to have his physical life extended unnaturally beyond what could be supported by reasonably ordinary means. It is almost impossible for the daughter and son to accept this decision of their father's because they each feel so guilty for their absence during the progression of his illness.

J. EXAMPLES OF ASSESSMENTS OF PATIENT/FAMILY NEEDS

Exhibit 29

In visiting with a new patient and his wife for the first time the nurse sensed a great deal of mutual constraint in the interaction. Her encouragements to be open about feelings were seemingly not received. However, later when the nurse met alone with the wife to discuss the patient's medication schedules the wife became more expressive about her feelings, sharing an overwhelming fear that her husband would not "hold together" throughout the ordeal. If he was unable to, the wife felt that surely she would be unable to. Later, when the nurse returned to the patient's room to find him crying, he startled and quickly corrected his behavior. In a subsequent discussion about feelings the patient independently noted the importance of his "maintaining" so as not to disturb his wife. The nurse determined that future visits to the home would always include private, quiet times for the patient and nurse to afford an opportunity for him to discuss his fears and cry.

Exhibit 30

Two widowed ladies seventy-two and seventy-four years of age had been the closest friends since early childhood. From the time that both had been widowed they had shared a home together and had a pleasant and relaxed lifestyle which suited them both extremely well. In the early spring the seventy-four year old woman was discovered to be in the early stages of an untreatable terminal condition. Referrred to the local hospice program, the woman remained home and received professional care through the hospice service while her companion was trained and supported to become an effective caregiver in the home. The course of the patient's illness was a predictable one and her housemate was a strong and reliable companion and caregiver during the course of her friend's illness. The patient's right to die at home was granted and she passed gently from this life in the presence of her friend and a hospice home care nurse. The seventy-two year old companion had been totally occupied twenty-four hours a day for many months in her willing dedication to her lifelong friend. After the death, the house was painfully silent and the hours were interminable. The hospice social worker and two very sensitive hospice volunteers made frequent visits to the surviving friend and ultimately she joined the hospice's support group for families of other previous hospice patients.

Exhibit 31

A hospice home care patient of four months suddenly insisted upon being admitted to the hospice inpatient unit even though his physical condition did not necessitate inpatient care at the time. The patient had been well maintained at home through periodic medical team assessments and weekly visits of the hospice home care nurse. His wife was physically capable and gave every indication of being able to provide for his modest daily needs. The second time the patient came to the hospice inpatient unit demanding admission he finally admitted that his wife had frequent temper tantrums at which time she repeatedly accused him of abandoning her. It was suddenly made painfully obvious to the entire hospice team that the wife needed substantial help in accepting the reality of her husband's ultimate death. The patient was at once admitted to the inpatient unit of hospice on a respite basis. The hospice team including social worker, chaplain and psychologist worked intensively to help the wife gain a more composed acceptance of the reality of her husband's physical condition. The patient was able to return home until shortly before his death when he was readmitted to the hospice inpatient unit for the last several days of his life.

K. EXAMPLES OF WORK ENVIRONMENT OF STAFF

Exhibit 32

A thirty-three year old nurse has been working on the hospice inpatient unit for five months. Her performance has been excellent in every respect as a competent clinician skilled and knowledgeable in the nursing arts and in the specialization of oncology nursing. She is well liked by other members of the nursing staff and other helping professions on the team. She works sensitively and gently with both patients and their families. One day she asks to see the Director of Nursing Service privately; as soon as they are alone the nurse breaks into deep but restrained sobbing. Once she has regained some composure she tells the Director that as difficult as it is for her to leave hospice, she really must resign as quickly as a replacement can be found. The discussion finally discloses that her husband is very opposed to her working in a hospice program. The home situation has deteriorated so that now the husband will not even let his wife touch him because she has been "handling dead bodies all day".

Exhibit 33

One hospice program employs a system whereby nursing services of both home care and inpatient care are each a single integrated nursing service. At one of the monthly scheduled staff meetings members of the nursing service begin to discuss their frustrations with certain aspects of their different individual roles. Home care nurses complain that they work for months with patients and families in their homes becoming well acquainted with them; close and deeply caring about them; only to have some patients transferred to the inpatient hospice service where they no longer have contact with them. Similiarly, nurses from the inpatient hospice unit feel oppressed because patients admitted to the inpatient hospice unit are usually in severely advanced stages of their terminal conditions and, subsequently, are inpatients for a comparatively short time. Therefore loss is experienced repeatedly and frequently and its nurses have no opportunity to get acquainted with patient and family before extreme physical deterioration occurs. It is decided in this staff meeting that a system would be instituted for three months and then evaluated for its usefulness, wherein individual nurses who choose to participate could be periodically rotated on assignment through both home care and inpatient services.

Exhibit 34

An evening staff nurse on the inpatient unit of a hospice had cared for a ninety-one year old lady for seven months since her admission. At the time of admission the patient was not expected to survive more than several days. She and this evening staff nurse had developed a deep and important bond between one another during the long hours of the evening when the patient so frequently was unable to sleep. Many times on her day off the nurse would stop by to visit the patient and bring her daughter and son to visit with their mother's elderly friend. Quite naturally, the patient gained great strength and comfort from the friendship of this loving and caring person. The evening nurse left the hospice one evening for her scheduled two days off. Before leaving the unit she stopped to see her patient-friend but she was sleeping and the nurse went off duty. On her return, she arrived early for her 3:00 p.m. report time in order to have a short visit with her friend before going on duty. She entered her friend's room only to be greeted by a total stranger in the bed that had been her friend's. She backed out of the room and moved slowly, blinded by tears, to the nurse's station to have the tragic truth confirmed. In the pressure of work on the unit the previous few days no one on duty had thought to call her and tell her of the death of her friend.

CHAPTER III. ILLUSTRATIONS OF HOSPICE ISSUES IN HUMANISTIC PATIENT CARE TRAINING

Once staff persons have a heightened awareness of some of the more frequently presenting variables which influence a patient's or family's feelings, attitudes, and/or behaviors concerning their current life circumstances, it is important to begin an examination of staff's own feelings, attitudes and behaviors. Patient/family values are not the only value systems of consequence in the creation of a care plan. The values of care providers may well validate or, in fact, contrast the values of those persons they will care for; thus it is important that all staff be aware of how personal attitudes and values may impact and influence the provision of care.

Through the use of vignettes (Exhibits 2-34) in the preceding chapter contrasting and conflicting examples of patient and staff values and attitudes have been presented briefly as they may occur within each of the eleven content areas to be examined in humanistic patient care training:

- Patient/Family Interactions
- Psychosocial Aspects of Aging
- Psychosocial Aspects of Illness
- Psychosocial Aspects of Dying
- Psychosocial Implications of Cultural Background
- Psychosocial Implications of Spiritual Background
- Patient Care Environment
- Maintenance of Patient Independence
- Patients' Rights
- Assessments of Patient/Family Needs
- Work Environment of Staff

An orientation to some substantive information in each of these areas, coupled with an awareness of the potential for contrasts/conflicts in values or attitudes, prepares the care provider for a more in depth examination of process skills, which when modified in response to what has been learned, favorably influences the provision of humanistic patient care. These process issues, or skills, are illustrated through the use of vignettes (Exhibits 36-56) similar to those found in Chapter II. The seven process issues which are the subject of this chapter follow:

- Intrapersonal Awareness
- Interpersonal Awareness
- Listening
- Communication (verbal and non-verbal)
- Learning/Teaching
- Stress Management
- Management and Supervision

The following matrix, Exhibit 35, displays the eleven content areas previously discussed (Chapter II) along the horizontal axis. The vertical axis indicates the process issues, or skills, which can be learned or further developed by hospice care providers. Any frame on the matrix created by the intersection of a process issue and a content area reflects the application of one specific skill in the processing of a problem or a value conflict relating to a particular content area.

The matrix is not intended to imply a mechanical approach to formulas for performance or behavior; rather, it is intended to assist in the analysis of specific situations. An issue which warrants processing may arise between care providers on a team, between care providers and patients/families. The matrix can be used by the trainer as a means of assessing the skills of a patient care team or by individual care providers as a self-assessment instrument used to determine the degree of comfort and skill possessed in working through problematic issues within each of th- defined content areas. The matrix may trigger thoughts of issues or problematic interactions concerning one of the content areas. Frequently, a closer examination of a particular scenario will reveal to staff areas where they, as a team, might have been able to improve upon the humanistic care provided.

The training materials contained in this monograph (Chapter IV: Approaches to Training) address each of the quadrants of the matrix through ten training sessions in five broad categories:

- Humanistic Patient Care Definitions, Components and Applications
- Psychosocial Variables in Working with the Dying Patient
- Patient and Family Needs, Environment and Rights
- Communication Skills and Styles: Patient/Staff Relationships, Staff/Staff Relationships and Other Health Professionals/Staff Relationships
- Monitoring of Humanistic Patient Care Provision

Exhibit 35

PROCESS ISSUES/SKILLS \ CONTENT AREAS	Patient/Family Interactions	Psychosocial Aspects of Aging	Psychosocial Aspects of Illness	Psychosocial Aspects of Dying	Psych. Implications of Cultural Background	Psych. Implications of Spiritual Background	Patient Care Environment	Maintenance of Patient Independence	Patients' Rights	Assessments of Patient/Family Needs	Work Environment of Staff
Intrapersonal Awareness											
Interpersonal Awareness											
Listening											
Communication (verbal & non-verbal)											
Learning/ Teaching											
Stress Management											
Management & Supervision											

The following vignettes each illustrate how skills may have facilitated the provision of humanistic patient care. For each process skill (issue) three vignettes have been prepared from actual hospice experience* which offer examples of staff use, or lack of use, of process skills. A matrix appears prior to each collection of vignettes addressing a particular process skill indicating, by vignette exhibit number, the skill and one or more content areas being illustrated.

* The ELM Institute wishes to express special appreciation to Mr. John A. Hackley who contributed personal illustrations (exhibits) appearing in this chapter. Illustrations reflect actual hospice experience.

A. ILLUSTRATIONS OF ISSUES IN INTRAPERSONAL AWARENESS

PROCESS ISSUE/ SKILL	CONTENT AREAS ILLUSTRATED IN EXHIBITS 36-38						
	Pt/Family Interactions	Psychosocial Aspects of			Pt Care Environ	Pts' Rights	Assmt of Pt/Family Needs
		Aging	Dying	Culture			
Intrapersonal Awareness	38	36	38	36, 37	37, 38	36	37, 38

Exhibit 36

A hospice nurse on an inpatient hospice unit has recently completed her first continuing education course in gerontology at a local liberal arts college. She found the experience to be very stimulating and it reawakened her long neglected interest in the psychosocial elements of "total person" care of older patients. She privately vowed to consciously strive to foster with her patients such beneficial activities as communal dining because of the social stimulation and other interaction benefits she realized could accrue. The very next day she approached one of her patients, an elderly widow of a long deceased prominent local judge. The patient was nearly 80 years of age, wheelchair-bound, always immaculately groomed, quite alert but unable to communicate well because of residual partial aphasia and right-sided facial paralysis from a stroke suffered two years earlier. While the nurse was busily releasing the brakes on the wheelchair, adjusting the foot supports and tidying the lap robe over the patient, she announced to the patient that she no longer would be served luncheon in her room but would be joining other hospice patients in the dining room. The nurse left the room and instructed a nursing assistant to wheel the elderly lady to the dining room for lunch. In no more than ten minutes, the nurse looked up from her work at the charting desk to see the elderly lady being wheeled back to her room. She was slumped to one side in the wheelchair, eyes red and swollen, cheeks glistening with tears and spittle oozing from the paralyzed corner of her mouth. The nurse followed the attendant and patient to the patient's room and assisted the attendant in returning the patient to her bed while her rasping sobs continued. Much later the nurse learned that the patient was humiliated to eat in the presence of others because her residual paralysis made her an "untidy" eater, and she was ashamed to be seen this way.

Exhibit 37

The present hospice administrator is resigning at the end of next month to move his family. One of the candidates for his position is visiting the hospice program for a day and during his visit he is shown a small unoccupied patient unit on the grounds of a nearby hospital. The hospice board of directors is considering the space for acquisition in the future to add the inpatient care component to the existing hospice service. In a meeting with the search committee and the present administrator the candidate is asked what his impressions were of the building being considered for eventual use as the hospice inpatient unit. The candidate expressed that he was very disappointed by the smallness of the patient rooms because they would not accommodate three patient beds in each. He understood from writings about the British hospice experiences that three-bed rooms were most preferred because patients could be supportive of each other and, should one die, the two remaining occupants would not be so devastated by the loss of the third. But more importantly, he emphasized it would be much more lucrative to get as many patients in each room as the licensure regulations would permit. That evening while being driven to the airport by the hospice administrator, the candidate recounted a humorous experience he had while he was a patient in an acute hospital recently. The administrator asked whether he had been in a medical unit or a surgical unit. The candidate stated that he had a routine appendectomy and was in a private room on a mixed medical-surgical floor of the hospital. The administrator asked why a private room on a mixed medical-surgical floor had been necessary for him post-operatively. "Oh, it wasn't necessary," replied the candidate, "but my privacy is very important to me, you see."

Exhibit 39

During the course of a regularly scheduled hospice team meeting to review selected patients in the program, the medical director asked the social worker for the outcome of her conversation with a patient's wife about having the patient admitted to the hospice inpatient unit for a short respite stay. "I don't understand it myself," the social worker remarked. "I talked with her for almost two hours and she could never see the personal benefit of my recommendation of a respite stay in the hospice for her husband. She has been caring for him at home now for almost five months, twenty-four hours a day. Of course, our home care nurse is in twice a week and there are volunteers to do errands for her as well as one male volunteer to do her heavy chores . . . but she never has any time to herself. I know I couldn't stand it. I'd have cabin fever. I need my routine share of private time to myself. Why, in our three years of marriage, my husband and I have always taken solo separate vacations. We each respect the solitary needs of the other." The home care nurse interrupted at this point to inquire, "But did the wife tell you that in their thirty-one years of marriage they have never been apart from one another for even one day? Even their two children were born in the home and the husband was right there, always at her side."

B. ILLUSTRATIONS OF ISSUES IN INTERPERSONAL AWARENESS

PROCESS ISSUE/ SKILL	CONTENT AREAS ILLUSTRATED IN EXHIBITS 39-41							
	Psychosocial Aspects of				Pt Care Envir	Pts' Rights	Assmt of Pt/Family Needs	Staff Work Envir
	Aging	Dying	Cultural	Spiritual				
Interpersonal Awareness	39,41	39	41	41	39	41	39	40,41

Exhibit 39

The staff of a well established eight-bed inpatient hospice unit had agreed at the last monthly staff meeting to "take a page" from the experience of a neighboring hospital and begin to institute some quality assurance strategies. One of the first exercises the staff decided upon, because of its directness and simplicity, was a patient satisfaction survey. Trained volunteers from the hospital Gray Lady unit were recruited to be interviewers so that patients and families would not perceive them as hospice representatives; thus, could better elicit candid responses. One hospice home care patient who was interviewed was a seventy-two year old single woman who had been a grade school teacher for over forty years. She had originally come into the hospice program as an inpatient- very ill, disoriented, experiencing frequent severe pain and totally disinterested in her surroundings. Within a few weeks she had responded so well to the hospice regime and the comprehensive care provided that she was able to return to the apartment that had been her home for over eighteen years. During her interview with the Gray Lady volunteer, the patient was asked to rank in a sequence of 1 to 5 those services/persons of the hospice program that she felt had most contributed to her well-being since being admitted to the hospice program. Without hesitation, the patient identified, by name, the occupational therapist of the hospice staff as number one, "numero uno". The volunteer asked of the reasons for choosing the O.T. as number one. Replied the patient, "she has taught me to knit, which I always wanted to do. She has introduced me to tape recordings of 'best seller' books which I enjoy every day. She has shown me how to pick up things I drop on the floor which I haven't been able to pick up comfortably in years. But, it's really none of these. My real improvement began the day I met her. She entered my room smiling and with a gentle touch of music in her voice. I remember that moment, oh, so well. She sat beside my bed, right up next to it, you know. She looked me right in the eyes and, I guess, she read there what I thought was so skillfully hidden; the shameful truth that I yearned to be touched- to be touched with caring. I hadn't been touched that way, you see, in over twenty years... not since my mother died. Well, that day that lovely young lady took one look and read it all, I guess. She took my hands in both of hers without ever referring to it and we had the most charming conversation. She didn't release my hands until she rose to leave and we were both amazed to see we had talked for forty minutes. I began to feel better from that day forward."

Exhibit 40

The weekly meeting of the hospice team to review individual patients/families for which it is responsible had been in process for some time and the session is moving toward a natural closure. Unexpectedly, one of the home care nurses announced that she would like to comment on the last case being considered; she had been the home care nurse for this patient for some time and there was something she "just had to get off her chest". She admitted she had never had the courage to put it into words before to any other hospice team members but she felt very guilty about not having been doing a "totally desirable job" on this case for many weeks. She acknowledged her promptness for every scheduled visit; that during every visit she had routinely provided all of the indicated and prescribed care for the patient; and that her concern and care for the patient was sincere. However, she expressed that she always felt that somehow she was not recognizing, and thus, not meeting, some of the psychosocial needs of the patient. This sense of failure was a constant burden on her conscience. It was such a growing and uncomfortable sense of inadequacy that she had never been able to articulate these feelings to any other team members. Quite surprisingly another team member spoke up at once and said, "That's it! Now I see what the problem has been. I'm afraid I have been misreading it, and you, for too long a time." She went on to say that she had become aware some time ago that in each team meeting when this particular home care patient was discussed, the home care nurse had become uncommonly quiet and contributed only minimum routine information. This second nurse had come to interpret the lack of responsiveness of the home care nurse as a lack of interest or dislike of the patient. The second nurse acknowledged that she was beginning to have very hostile feelings toward the home care nurse for presumably not really caring intensely enough for this patient. Once the air had been cleared, the first nurse's feelings of inadequacy and sense of frustration, engendered because she really did care but didn't know what more to do, were out in the open and could be appreciated and shared. It was now open for a resolution of these feelings with the help of the other team members.

Exhibit 61

Mrs. Bob, and Mr. S. are both seventy-one years of age, each a surviving spouse and each having been widowed for some time. This couple has been dating for almost two years and wished to marry but finally 'set to admit that this would be impossible since Mrs. Bob would lose her pension if she remarried, and the two could not survive on the single small fixed income of Mr. S. The couple decided to forego the legal exertion of marriage and since then have shared the small home of Mrs. Bob. For the past few months Mrs. Bob. has been a patient on the home care rolls of the hospice program. She has been receiving two home care nursing visits a week while Mr. S., as the significant other, cared for her very competently on a routine daily basis. The home care nurse who had been assigned to Mrs. Bob.'s care since the beginning recently asked her supervisor to remove her from the case, and assign her another home care patient. She was very vague and nonspecific about the reason for the request of assignment change, but nevertheless, the home care supervisor respected the nurse's request and a second home care nurse was assigned to Mrs. Bob. The new home care nurse assigned to Mrs. Bob. visited the home on the prescribed day, provided the indicated specialized care and often lingered over a cup of coffee to chat with Mrs. Bob. and Mr. S. in order to become better acquainted. The exchanges were pleasant and rapport seemed to be established comfortably. On her second visit to the home, Mr. S. mentioned to the nurse that he was happy for the first nurse that she no longer had to come to their home. "She never said a word about it, she wouldn't. She was too tied a person. But I just know she was always so painfully uncomfortable with the knowledge that Mrs. Bob. and I are not married. I'm sure it is more comfortable for her visiting some other family instead of us."

C. ILLUSTRATIONS OF ISSUES IN LISTENING

Practice Cases/ Drills	Content Areas Illustrated in Exercise 62-64						
	Pt/Fam Interaction	Psychosocial Aspects of Dying	Pt Care Environment	Patient Independence	Pts' Rights	Needs of Pt/Fam	Staff Work Envir
Listening	64	62,63	62	62	62,64	62,63,64	64

Exhibit 62

A middle-aged lady had been terminally ill for over two years. Seven months ago she was admitted to the hospice home care program. Eight days ago she was admitted to the inpatient hospice unit because it was quite apparent that death was imminent and her paid companion could no longer provide the intensive round-the-clock supervision that was required. The patient was very comfortable being in the inpatient hospice unit. After all, she had been there at one time as a day care patient; twice she had been there on a respite visit when her companion had family emergencies. She now knew some of the patients and many of the staff and volunteers. Late one afternoon her vital signs gave every indication that death could come at any time. The nurse did not want her to die alone - no one had to die alone at hospice - and, so she sat quietly for a very long time close to the side of the bed. She thought the patient was sleeping because she was very still and her breathing was regular, although shallow. Suddenly the patient opened her eyes and turned her head to look at the nurse. "I understand what you are doing," she said softly, "but it really isn't necessary. I am comfortable. I've prepared for this test and I want to take it alone." The nurse understood completely and respected the patient's choice. She kissed the patient's forehead, gently squeezed her hand and placed in it the call bell control so that she might signal for her if she changed her mind. She then quietly left the room. Ten minutes later the nurse softly entered the doorway to check on the patient and found that she had quietly, gently and apparently, painlessly, expired.

Exhibit 43

The hospice home care nurse was making her usual visit to an eighty year old home care patient. He was a dapper little man, always very chipper and cheerful. Jovial remarks were his hallmark. His daughter had come from Virginia to stay with him and care for him during this illness. Although his physical condition was obviously deteriorating, he still was glib and ended each of her visits with a lighthearted "See you." Today, however, he seemed weaker, more fragile and, to the nurse, appeared "vulnerable" for the first time since they had met. There was a smile on his lips as always but it too was a bit fragile today. As the nurse prepared to leave after her visit, she gave some last minute instructions to the daughter and then stuck her head in the patient's room again before she left. "Goodbye, Judy Dear," he said with a fuller and more genuine smile. The nurse returned to her car, closed the door, and put the key in the ignition, when suddenly tears welled in her eyes and she realized it had not been "See you," but today it has been "Goodbye, Judy Dear." She dried her eyes and returned to the home. She entered the patient's room where he looked up questioningly and inquired, "Did you forget something?" "Yes, Mr. Crawford, I forgot to tell you that when we are not together, I miss you very much."

Exhibit 44

A new hospice nurse has just returned from her first visit to a sixty-six year old man who is suffering from advanced lung cancer. The weekly care review session of the hospice team is scheduled for the afternoon. When it comes time to discuss the elderly male patient, the new home care nurse inquires how this patient ever came into the hospice program. She had understood that patients in order to be admitted to hospice, must be aware of their terminal conditions. She reported that the patient had told her he had asthma and was only in the hospice program until he gained enough strength that he and his wife could move to Arizona where the climate was more comfortable. Upon hearing this, the other members of the team assured her that his family physician long ago had fully apprised him of his prognosis and that his condition and its advancing severity had been discussed openly with him in patient care planning conferences. Suddenly, the home care nurse, with a very knowing expression, remarked, "It's the wife, isn't it, who is not accepting as part of his condition?" The team members assured her that it was. "Well, of course, he was telling me that his wife, who was in the room, should not be brought into our discussion of his actual condition."

D. ILLUSTRATIONS OF ISSUES IN COMMUNICATION (verbal and non-verbal)

PROCESS ISSUE/ SKILL	CONTENT AREAS ILLUSTRATED IN EXHIBITS 45-47			
	Psychosocial Aspects of		Assmt of Pt/Fam Needs	Staff Work Envir
	Aging	Culture		
Communi-cation	47	47	45	46,47

Exhibit 45

A wife of fifty-one years has been caring for her husband at home; he is slowly deteriorating from a long-diagnosed terminal condition. For the past few months this couple has been in the home care service of the hospice program. The wife has been very cooperative on the surface and has genuinely been grateful for the presence and help of the hospice physician. However, other team members realize their relationship with the wife is not as open, direct and sincere as it should be, and hopefully, will become. One day while the home care nurse is with the patient tightening the bottom sheet on his bed, his wife enters the room. "I just changed his bed an hour ago! Didn't I do it good enough?" she demands. Rushing from the room, she begins to weep. The nurse covers the patient and follows the wife into the kitchen where she is now sobbing uncontrollably. The nurse sits beside her and says, "He had been moving about in bed and I was merely removing some wrinkles that had developed." Her hand reaches out and rests on the wife's arm. "Aren't we fortunate that from time to time tears can wash away our anger over things we cannot change?"

Exhibit 46

Toward the end of a monthly staff meeting, one team member asked of the others who might have told the wife of the home care patient being discussed that hospice could provide only a maximum of two home visits a week. Each member of the team denied that he or she had ever told anyone that. The inquiring team member, a home care nurse, then reported that the last time she was in the patient's home, the patient seemed to have deteriorated markedly. When she left the home the wife had walked with her to her car and, fully aware of the worsening of her husband's condition, quite agitatedly asked, "This is your second visit this week. Now where can I turn if we need help before next week?" A thorough canvass of all hospice staff finally revealed that the young man who is the business office manager had told the wife when she last came to the hospice business office that her coverage allowed a maximum of two home visits a week. It was a sad discovery to learn that other hospice staff had failed to tell this business manager that hospice made home visits whenever there was a need. It ultimately dawned on the caregiving staff of hospice that all hospice staff and volunteers are on the team. Whether it is recognized or not, every individual impacts both patients and families.

Exhibit 47

At one of the hospice staff support sessions, a nurse on the inpatient unit of the hospice program remarked that she was at "her wit's end". She had attempted to see God in her fellow man, she continually tried to love each patient for whom she cared, but there was one patient whom she not only could not like but was gradually coming to dislike. She pleaded that she was really at a loss to create for herself a mindset that would help her to successfully overcome her growing aversion to this particular male patient. The situation she described was one of a sixty-seven year old male patient who had been in the hospice inpatient unit for three weeks. He had been admitted because his wife had become totally exhausted after months of around-the-clock care of the admittedly "difficult" patient. The nurse noted that one particularly distasteful condition was the care of this man's incontinency of bowel. Not, she professed, that this was an uncommon condition requiring nursing care of an unpleasant nature. Rather, it was that at the time of these accidents when the nurse would be cleaning the patient and changing his bed linen that the patient would take these specific opportunities to vent his anger and to be particularly verbally abusive toward the nurse. The social worker and the medical director joined one another in helping the nurse to make a realistic and insightful interpretation of the patient's own behavior; this would assist the nurse to become more objectively perceptive of what was actually being communicated by the patient. It was brought out that, given the age of the patient, what was known of the sociocultural milieu from which he had come, and the extreme personal shyness of the patient (attested to by his wife on more than one occasion), the patient probably suffered painful humiliation whenever he was incontinent of bowel. Inasmuch as he was reared with the "male image" that did not permit evidencing shame or humiliation, he employed the only alternate response he thought was permissable in the male role -- that of an insensitive and blustery facade. Given this enlightened interpretation of what the patient was in fact communicating, the nurse was able to return to her care of the patient with a much more understanding and accepting frame of mind.

E. ILLUSTRATIONS OF ISSUES IN LEARNING/TEACHING

	CONTENT AREAS ILLUSTRATED IN EXHIBITS 48-50					
PROCESS ISSUES/ SKILLS	Pt/Fam Interac-tions	Psychosoc Aspects of Illness	Psychosoc Aspects of Culture	Pt Care Envir	Patient Indepen-dence	Assmt of Pt/Fam Needs
Learning/ Teaching	48	50	49	50	50	48,49,50

Exhibit 48

A lady in her late thirties lives in the same community as her mother. They see one another each week and have had a very good relationship for as long as either could remember. The mother goes out socially with her daughter, son-in-law and three grandchildren at least once or twice a week. Five months ago the mother was diagnosed as having inoperable cancer and her family physician suggested she explore the local hospice program to become familiar with the program and its staff and also have the preliminary admission protocols taken care of before it may become necessary to go on home care. The mother requested the daughter to accompany her to the hospice for the initial contact and while the mother met alone with the medical director, the daughter was interviewed by the hospice social worker. While she was talking with the social worker, the daughter admitted her apprehension and perplexed feelings about how to discuss with her mother the recently diagnosed condition and the negative prognosis. The daughter remarked, "I just don't know how to best broach these matters in open conversations with mother. Each time we are together, I find myself chattering like a magpie about all kinds of trivia -- filling any otherwise awkward silence. I've never been uncomfortable with mother but I just don't know how to talk with her about this." The social worker responded, "Try silence. Your constant running conversation about inconsequential things probably is seen by your mother as a signal that you don't want to discuss her condition at all. From now on when you are together, help yourself be comfortable with silent periods that normally arise. Eventually, when she is ready, your mother will bring up the subject. She will give you adequate subtle or overt clues as to how she wants the two of you to handle the situation. You will be pleasantly surprised at how naturally the situation between the two of you will unfold into a mutually comfortable sharing."

Exhibit 49

An attractive and charming lady of sixty-two years recently died on the inpatient unit of a hospice program. She had been an inpatient for three weeks prior to her death and prior to that she had utilized both home care and day care facets of the hospice service. Her husband, a respected professional leader in the mental health field, had been a devoted spouse; he was very solicitous, supportive and understanding during her prolonged illness. He was an inexhaustible caregiver while his wife was in the home and also when she was on day care. A few days after his wife's funeral, the husband stopped to visit the administrator and others on the hospice staff. After expressing his and his adult children's sincere appreciation for the care and understanding his wife and family had received from hospice, he went on to state he thought the hospice bereavement services for surviving families was an excellent service but, of course, he wouldn't need bereavement support because he was a mental health professional. Nevertheless, a couple of weeks later the husband again visited the inpatient hospice unit and remarked that he had just come from his own doctor's office where he has his blood pressure checked twice a week. He expressed that it really would be more convenient for him, and his physician approved of the husband's suggestion, if he could stop by hospice twice a week on his way home from work to have his blood pressure taken. The hospice nursing staff was pleased to oblige. The husband stopped twice a week as planned, often lingering over coffee for some reminiscing about his wife or to talk to other patients and their families. Many weeks later,as he was speaking with the hospice social worker, he admitted, "I guess I really did need bereavement support but it has taken all these weeks to learn that is what I was seeking."

Exhibit 50

A woman in her late fifties was admitted to the hospice home care program. She lived alone and managed well most routine activities and daily household responsibilities. A married daughter and a single son in the same community, both of whom were close to their mother, visited her often and were very supportive. The mother, however, would not let her children or friends do any of the home management tasks for her because it was very important to her that she remain as totally independent in her daily routines and lifestyle as was humanly possible. Her personal pride was wholesome and admirable. Gradually, however, her strength and physical endurance began to mildly diminish and she feared she would become "prematurely" dependent. The hospice home care nurse, who had a rehabilitation nursing background, and the hospice occupational therapist assisted in many innovative ways to help encourage her drive for maintaining personal independence. She was taught the technique of making her bed in a way that required only one walk around the sides of the bed. She was assisted in the reorganization of her kitchen so everything was within easy reach and frequently used items were most accessible. She learned how certain assistive devices could make it possible for her to do certain other tasks that otherwise she had become too frail to tackle in a traditional way. The patient teaching by the hospice home care staff helped add many more weeks to her independent functioning at home that might otherwise have been lost.

F. ILLUSTRATIONS IN STRESS MANAGEMENT

PROCESS ISSUES/ SKILLS	Pt/Fam Interac-tions	Psychosoc Aspects		Pt Care Envir	Pts' Rights	Assmt of Pt/Fam Needs	Staff Work Envir
		Illness	Spiritu-ality				
Stress Manage-ment	S2	S1	S3	S1,S2,S[illegible]	S3	S1,S2,S3	S1,S2

Exhibit S1

The hospice social worker walked into the staff lounge for a cup of tea to find a home care nurse, just having returned from the field, sitting with an untouched cup of coffee looking very forlorn. "I've just returned from the Belvedere area", she reported, practically in a monotone. "I've been working with that young family there for several months. There is just so much they need and my time with them seems so limited." She recounted the young woman's condition, "Her condition is deteriorating constantly and she needs progressively more frequent and longer rest periods in bed. She'll resist leaving home to the end because she realizes how much her children need her. Her husband is a tower of strength but he works 5½ days as a draftsman every week, does all the housework, laundry, cooking, yardwork, in addition to helping the eleven year old with her homework and the seven year old with his spelling and his soccer. Even then, he's still up several times during the night to perform care routines for his wife." The home care nurse visited as frequently as professional nursing care intervention was indicated but she had become so devoted to the young family and so sensitive to the needs of the two youngsters had for a mother in their little daily life crises that even when she was off duty and away from hospice she was ever more preoccupied with their needs. The social worker listened intently as the nurse gradually exhausted herself recounting to him a-l the details of each family member. It took time and several sessions with the home care nurse, but gradually the social worker was successful in helping her realize that she alone was not responsible for, and couldn't physically endure, meeting all the myriad number and kinds of needs the whole family had. Volunteer help was obtained through the patient's church congregation. A part time home health aide was arranged for through the VNA to manage some of the husband's homemaking responsibilities. Ultimately, the nurse felt much less pressure, much less overwhelmed and could begin to prioritize her efforts between care for the woman and support for the husband in his role as part time caregiver.

Exhibit 52

Mid-morning, early in the week, the hospice received a near hysterical call from the thirty-nine year old daughter of an aging home care patient who, it would appear, had taken a sudden critical turn for the worse. The assigned home care nurse was contacted in the field and arrived at the home within a matter of minutes. Shortly thereafter, she, in turn, contacted the hospice home care coordinator with the request for additional available hospice staff persons and volunteers as soon as possible. The patient truly had taken a very sudden turn and was only intermittently aware of her surroundings. The patient's daughter was hysterical; the patient's two sons were quarreling about which one had done more for the parents, heaping recriminations upon one another in loud angry voices; five grandchildren of varying ages were vacillating between tears and demands to be fed; and the husband sat trance-like in a rocker on the porch, unable to help anyone including himself. The hospice medical director and another home care nurse arrived and assumed responsibility for the patient's care. The patient's minister appeared with three women from the church. The church ladies took over management of the home and food preparation. Just as the minister was about to leave with the two sons in his car, the hospice social worker arrived to escort the much subdued daughter to a neighbor's home where it was quiet and she could receive help to gain composure. The original home care nurse sat with the grief-stricken husband on the porch, quietly comforting him in his sorrowful vigil.

Exhibit 53

Three women, all in their seventies, were patients in the hospice inpatient unit. Mrs. T. had been an inpatient for two months, Ms. H. was admitted from University Hospital two weeks ago and Miss W. had been there 3½ weeks. They were each admitted to the same 3-bed room upon their respective arrivals which proved to be a mutually compatible situation. They shared their concerns as well as their humorous memories with one another, just as they shared their visitors, families and gifts of flowers and sippin' whiskey. As each knew in the private recesses of her heart that a time would come when each would die, death did indeed come to Mrs. T. quietly in her sleep just an hour or so after her son had called from Juneau. The hospice nurses closed the cubicle curtains around Mrs. T.'s bed and unhurriedly and very respectfully prepared her for departure from hospice. When the nurses came out of the cubicle curtains, Ms. H. and Miss W. asked if the chaplain could come to see them and pray with them and be with them as they said their goodbyes to Mrs. T. before her body was taken from the hospice. Later the two ladies told the hospice administrator that the next day Miss W.'s nephew was bringing a rose bush of the kind Mrs. T. most enjoyed. They asked the administrator to select the spot on the hospice grounds where this living memorial to Mrs. T. could be planted and join them and their friends - both staff and family - in the simple memorial service.

G. ILLUSTRATIONS OF ISSUES IN MANAGEMENT/SUPERVISION

	CONTENT AREAS ILLUSTRATED IN EXHIBITS 54 - 56			
PROCESS ISSUES/ SKILLS	Pt Care Envir	Patient Indepen-dence	Assmt of Pt/Fam Needs	Staff Work Envir
Manage-ment & Super-vision	54,55,56	56	56	54, 55, 56

Exhibit 54

One community hospice program had been in planning and preparation phases for almost two years; five days remained before it would admit its first patient. The staff had been meticulously selected and its orientation and initial training had been rigorous and extensive. The volunteers had been screened, oriented, assessed, trained, and even had had some field visits to the regional cancer center and the oncology unit of the local teaching hospital. Now was the hour for the first real staff meeting. Most persons at the meeting knew the hospice administrator through private and/or small group conversations but today was different . . . today everyone knew everyone's role within this group of hospice-focused employees and volunteers. Privately many wondered what tone would be set for the hospice program by the administrator, the focal point of this first meeting. The convictions that were laid out that day for all to hear included the following: "(1) Hospice care is ever a team effort, but not a team with a fixed and constant leader; leadership would evolve upon the one most competent in the major area of focus of the task at hand. (2) We - hospice staff, volunteers, patients and families - are not a structured establishment designed after traditional edifices; we are a family, a community, yet a caring community, of interdependent, caring and needing persons ever in flux - sometimes giving, sometimes receiving, always sharing." What kind of hospice program could be expected to emerge from this beginning?

Exhibit 55

A charge nurse of the inpatient hospice unit was enjoying a cup of coffee on her break with the administrator - a social worker by profession. It was a very quiet time -- no emergencies, no call lights burning, no furor; in other words, a rare moment. The tranquility of the moment made openness come early. The charge nurse told the administrator that when she joined hospice with this shift assignment, she expected that she would essentially be a partial member of the hospice team, not really vitally caught up in the dynamics of the "visible" hospice. After all, she had often been on the 11 p.m. to 7 a.m. shift in other inpatient programs and,routinely, staff on this least envied shift merely held things together for the visible day shift heroes. She was used to that and it was what she expected. Management and "daytime" department heads wouldn't even know her name or that of her associates on this shift. However, she learned that wasn't the case at hospice. At least twice a week the director of nursing visited her shift -- not for a five minute "How do you do?" but for a truly unhurried useful extended period of time. Twice already, the staff development coordinator had visited to get their views on the effectiveness of staff training and their recommendations for improving the staff development program. Educational sessions were planned for their convenience, sensitively aware of their real needs and their unique social hours and needs. She reported, "It's not bad at all being on this shift that is considered by many to be undesirable." The administrator looked her kindly in the eye and asked, "How could it be considered undesirable? You know, statistically, the angels visit this shift more often than the other two shifts put together."

Exhibit 56

One day the administrators of a 1,100-bed teaching hospital, a nationally prominent radiologist and the chief of oncology, both from that same hospital, and the dean of the medical school came as a group, 2,100 miles to visit a hospice program they had long heard of, and about which they had read extensively in the literature. They were eager to assess the potential benefits of instituting a hospice program in their own setting. They met with the hospice medical director and consulting medical specialists, the administrator and department heads. They toured the inpatient unit, read clinical records, visited with home care nurses, the chaplain, the social worker several referring physicians and numerous relatives. Toward the end of the day the visiting oncologist mentioned to the volunteer director that he had been impressed by a poem written in this hospice by a patient. He had assumed that the patient had since died but was informed she hadn't and was taken to the portico who sat in her wheelchair under the misty gazebo. He asked her what she found most valuable about this hospice program. With a tilt of the head, she said, "its personality, its ambience, its character -- no doubt you're amazed today to be a very special kind of cancer." He agreed that he had. "You see, there are plants everywhere, in every room -- thriving plants, many in bloom. You look out on this patio in the early morn and song-birds are having their morning splash in our fountain. The eight year old great-granddaughter of my roommate who died in April, came to have a picnic lunch with me here on the patio last Tuesday and she brought her rather special puppy to meet me. My good friend down the hall had suffered great nausea for weeks before she came here ten days ago. Yesterday morning at 3 a.m., she had a craving for Chinese food. She sent me a verbal invitation by the night nurse and would you believe that at 3:10 a.m. three of us were having egg rolls, almond chicken, fluffy rice, even eggs. It was quite an elegant party. This is truly a very special oasis in this world of ours. You will find that practically anything that is worthwhile is possible here. I must have been a butterfly in an earlier life because I still have very, very sensitive antennae and I can quite honestly tell you that in all the time this has been my home, I have never sensed even one iota of negative energy. That is why it is so compellingly obvious to all of us that only positive things can be expected to occur here."

CHAPTER IV. APPROACHES TO TRAINING

Having discussed both examples of content areas and process issues relevant to the provision of humanistic patient care in the hospital setting, it is now appropriate to introduce a structure which supports a forum for further exploration of topics and issues with hospital staff.

The remaining materials in this monograph, Chapter IV, offer guidelines for approaching the training in humanistic patient care. Drawing upon the eleven content areas identified in Chapter II:

- Patient/Family Interactions
- Psychosocial Aspects of Aging
- Psychosocial Aspects of Illness
- Psychosocial Aspects of Dying
- Psychosocial Implications of Cultural Background
- Psychosocial Implications of Spiritual Background
- Patient Care Environment
- Maintenance of Patient Independence
- Patients' Rights
- Assessments of Patient/Family Needs
- Work Environment of Staff

and the seven process issues/skills identified in Chapter III:

- Intrapersonal Awareness
- Interpersonal Awareness
- Listening
- Communication
- Learning/Teaching
- Stress Management
- Management/Supervision

the content and process in the design for training in humanistic patient care was developed. These eleven content areas and seven process issues were collapsed into a format which would permit a timely and comprehensive presentation and exploration of all points relevant to the provision of humanistic patient care by hospital staffs. This was achieved by developing five broad categories: four categories which contained actual training sessions (3 sessions), and a fifth category to address a critical issue in any training - monitoring. These five categories and the training sessions to be held within are:

A. Humanistic Patient Care Definitions, Components and Applications

- Session 1: Assessing Group Needs in Humanistic Patient Care
- Session 2: Humanistic Patient Care: Definitions and Components
- Session 3: The Application of the Humanistic Patient Care Approach

D. Psychosocial Variables in Working with the Dying Patient

- Session 6: Psychosocial Variables in Working with the Dying Patient

E. Patient and Family Needs, Environment and Rights

- Session 5: Factors Which Influence Understanding Patient and Family Needs
- Session 6: Identifying and Prioritizing Patient and Family Needs
- Session 7: The Patient Care Environment and Patient Rights

F. Communication Skills and Styles: Patient/Staff Relationships, Staff/Staff Relationships and Other Health Professionals/Staff Relationships

- Session 8: Communication Issues and Skill Building
- Session 9: Patient/Staff Relationships
- Session 10: Interpersonal Skill Building as a Member of the Hospice Team

G. Monitoring of Successful Patient Care Provision

The clustering of topics and the sequence of sessions within each training category are suggested based on the interrelatedness of the subject matter. Trainers must utilize personal discretion in the determination of which topics are to ultimately be included in training and the timing for their introduction based upon participant preparedness, and hospice administration willingness.

In the development of these training materials the presence of high quality professional skills of staff has been assumed; that they are not a focus of this effort. The supportive patient care issues identified during the initial data collection period, the organization of the hospice staff, the composition of the group being trained, and the participants of what transpired in interdisciplinary team training previously are the variables of importance in the process in determining the training design for a particular hospice. The experienced trainer is the best judge of the emphasis to be placed on each of the training areas identified. Throughout these materials options have been offered for the "collapsing" of materials, recognizing that many hospices will not have the resources to implement a lengthy training program. It is recognized, however, that a trainer may identify a need for a greater emphasis on a particular topic or a "skill" that has been collapsed here. A greater emphasis either by the lengthening of individual sessions, or by adding sessions, is left to the discretion of the trainer, with assistance from the hospice administration.

Because not all hospice staffs have the same training needs, these materials have been designed in a fashion which permits their use in several ways. Whether each session is introduced as designed, collapsed and combined with other sessions, used in part, or omitted all together, the training design accepts a format which more readily responds to individual hospice needs and trainer discretion.

All sections of this chapter have continued to focus on the development of the trainer in preparing for training in a hospice setting. Toward this end, sections A, B, C, and D have been presented in the following consistent format:

1. Background Information for Trainers offers helpful hints to trainers about preparing for training sessions found in a particular category. Included also are suggestions on trainer behavior, timing of sessions, combining sessions when time or participant awareness does not support inclusion of all training sessions or parts of sessions.

2. Training Session Outlines draw upon the experience derived from previous training in hospice patient care to offer trainers a guiding format for conducting training (both content and process are offered). Small group activity is used as the primary methodology in training, aimed at building strong, positive relationships among participants to enable the focus on tasks in training.

3. Examples from Hospice Training Experience cites pertinent examples of presentations, discussions, and materials used in previous training sessions such as visual aids, handouts, written exercises, and homework assignments. This section is intended to offer trainers a flavor of the training environment under the basic resources hospice-location contexts.

4. Selected Resource Materials offer both trainer and participants a selection of literature which provides additional topic-specific information on those areas and issues addressed in training. These resources are in addition to those cited for the trainer's use necessary for preparing for individual training topics.

Section E, monitoring of homecare patient care provides, offers suggestions for the trainer about monitoring during the "hands-on" training activities and suggests a model that the trainer is to share with participants in support to their use sessions with-homes activities. This training is in no way intended to provide all that is necessary for a hospice team in homecare patient care, thus the need for staff to monitor their use activities. The application of values, the consequences of use information and skills, and the application of these in the hospice setting are all team-management activities requiring time.

A. [illegible]

This section provides the trainer with pertinent background information; these sessions outline initial and on assessment and ban on the definition and application of humanistic patient care in the hospice setting; and multiple topic related examples from the training experience. The manner in which humanistic patient care issues are identified within a hospice are addressed in these sessions.

1. [illegible]

(a) Sequence of Sessions

Because it is the intent of the training program to heighten the awareness of basic care providers in hospice settings, thereby enabling an increased ability to provide humanistic patient care, there are three major areas which must be addressed: the knowledge and understanding of humanistic factors which affect illness, the care provider, and dying; the skills inherent in the development of effective relationships which contribute to the provision of humanistic care; and the personal development necessary for assessing the concepts and mastering the skills. Before content areas can meaningfully be addressed or humanistic skills identified, it is necessary to focus upon the individual care provider. The experiential learning required in humanistic patient-care training may initially prove difficult for some participants. The format of much of the training encourages the open participation of all. Initial sessions are designed to build trust and employ a sense of community so much an ongoing definition of humanistic patient care. This trust is necessary for the expression of both interpersonal and intrapersonal issues and the subsequent sharing thereof of these issues. When the expression is the verbalization of a positive relationship which supports the patient's dignity and self-esteem, it is necessary to first explore those internal variables which govern the care provider. The first two training sessions addressed here provide the foundation upon which the concepts and skills areas are to be developed in forthcoming training sessions.

(b) Session Relationships to Previous Issues

The primary focus of the initial training sessions (two) is intrapersonal awareness. The materials provided offer an opportunity for the exploration of intrapersonal issues which relate to humanistic patient care. This exploration, as a method of process in group dynamics, contributes to a heightened intrapersonal awareness : first of factors hospice care providers, later to be addressed in the diverse populations of patients. Exercise and other learning experiences with peer participants are then introduced. Exchanges among participants are viewed both clinical and theoretical value systems. Participants can expect to

become more aware of conflicts within themselves and be supported by fellow care providers in working through these conflicts.

> Example: In one hospice training session the following exchange took place. (Participant #1) - "When I go into a home of an old Swede who is careless about taking meds, does not like to bathe - you have to start by insisting upon a regime; I go along with the ideal we talk about it, but when do the two come closer together? I guess it's my value judgment that it is more important to start a regime of care that I consider better care." (Participant #2) - "Who is to say that the patient can't choose to have pain rather than take medication? Who's to say she is wrong by not going along with what we feel is best?" (Participant #3) - "I guess the real focus is whether we were more to the left (stated values) or to the right toward actual values."

Exercises to determine what "humanistic patient care" means to each participant require an exploration of self, the examination of values, attitudes and beliefs. This inventory of self, coupled with an increased awareness of the values, attitudes and beliefs of fellow care providers, sets the stage for the further exploration of the myriad of variables - religious, social, familial, cultural - which will affect the provision of humanistic patient care.

(c) Timing of Sessions and Trainer Planning

Prior to the conduct of actual training sessions, an assessment of need for training was undertaken. Whether this assessment follows the structure of the initial session outline included within these materials, or is much more informal and individualistic, an assessment should be done by either the humanistic trainer-to-be or by the interdisciplinary team trainer. (In the case of the latter, he/she would share the results of the survey with the trainer who would develop the humanistic patient care program from these materials). In the actual training experience the assessment was performed immediately following the conclusion of the interdisciplinary team training, three months prior to actual implementation of the training. (It was determined that training would not be conducted during the summer months; the assessment at the conclusion of one phase of training and prior to the summer months, was timed in that manner to ensure the smooth transition from one trainer to the next). However, an assessment may be performed much more proximate to the associated training experience so long as there is sufficient time for the trainer to develop the training program based on the needs identified. (Note: It is recommended that interdisciplinary team training be conducted prior to humanistic patient care training).

In the actual training experience two sessions (three hours in duration each) were devoted to the exploration of "definitions" and "applications" of humanistic patient care. It is conceivable however, that these two sessions could be condensed to one (perhaps four hours in duration), depending upon the size of the group and the ability of the group to arrive at an operational definition of humanistic patient care. It is felt however, that the process of exploring attitudes, values and beliefs is crucial to the future development and training experience of participants, so ample time should be allotted for this process to occur. In the event that two sessions are to be conducted, they should be as proximate to one another as possible (e.g., sessions conducted back to back two days in a row) thereby facilitating the fullest exploration of values, attitudes and behavior. Further, other topics within the training program should not "piggyback" the initial training sessions to permit time for integration of the material from the first sessions.

Some process guidelines have been provided to trainers by means of stated time ranges for each activity offered in a training session. A range is utilized rather than a concrete time to account for variations in the size and need of groups. Rough estimates based also on hospice training experience indicate that a break of ten minutes is desirable per three hour training session. Though there are several brief presentations in the first two training sessions, the emphasis in time should be placed on group discussion and the experiential learning elements.

(d) Trainer Behavior in Opening Session

The following is a reminder of the major role behavior requirement of the trainer in the early sessions (see Monograph 2, Chapter IV).

- Facilitate open discussion but keep participants pretty much on track.
- Encourage participation from all participants within their level of comfort. Do not permit supervisory members to dominate. Emphasize the equality of all members within these training sessions.
- Provide support to participants working through conflict; avoid development of ambience conductive to "sensitivity session" or "T-Group" type activities.
- Ensure group understands trainer role, and behave so that group develops confidence in trainer and with the trainer's stated role.

2. OUTLINE OF TRAINING: HUMANISTIC PATIENT CARE DEFINITIONS, COMPONENTS AND APPLICATIONS

One group assessment session and two training sessions are outlined in this section for the trainer(s). The outlines provided are illustrative examples of how sessions have been conducted in training sites and are by no means a dictate of how training sessions must be conducted. Based upon the defined needs of each hospice group, time and resource limitations and trainer personal style, each session can be fashioned in a manner which responds to these needs, limitations, and personal style.

Session 1 Assessing Group Needs in Humanistic Patient Care

Purposes of the Session

- To explore participants' own definitions and components of humanistic patient care as relates to hospice patients, and
- To have participants identify own problem areas relevant to delivery of humanistic patient care.

Participant Preparation

- None

Trainer Preparation

- Review sections of the series: Monograph 2, Chapters II, III, IV, V; Monograph 3, Chapters II, IV, V, VI.
- Review, if desired, the following recommended major written resources:
  - Craven, J., and Wald, F., "Hospice Care for Dying Patients", American Journal of Nursing, 75, October, 1975, pp. 1816-1822.
  - Benson, H. et al., The Masculine Principle, The Feminine Principle and Humanistic Medicine, San Francisco, Institute for Study of Humanistic Medicine, 1975.

(Estimated Time for Activity)	(Activity)
(15-20 Min.)	Opening Remarks

- Introduce self (trainer) and any other non-participants (such as the recorder) present.
- Request participants to introduce themselves.
- Describe own role as facilitator. Identify role expectations for group. Identify person in charge and that person's role in the conduct of the training.
- Review the plan for all humanistic patient care training sessions and the responsibilities of the participants (i.e. homework, regular attendance, participation).
- Review the session's purpose, agenda and expected outcomes and ask for agreement from the group.
- Respond to any questions.

(135-145 Min.)	Exercise

- Request participants to explore own operational definition of humanistic patient care which relates specifically to hospice patients/families. Instruct each participant to write down all words/phrases which come to mind when "humanistic patient care" is mentioned.
- Develop composite list of words on a flipchart/blackboard based on each participant's personally developed list.
- Divide composite list (with participants) into two categories: words relating to information needs, "Content" and words relating to awareness or sensitivity development, "Skills".
- Refer to lists; solicit group's input for which items are to be explored in training sessions.
- Facilitate ensuing discussion about training needs using distinctions in the group between "intrapersonal" and "interpersonal" aspects of awareness in skill development.
- Develop tentative list of training topics, seek concurrence from group.

(Estimated Time for Activity)	(Activity)
(10-15 Min.)	Closing Remarks

- Seek agreement from the group for the proposed schedule for the training sessions. Make adjustments to the schedule as necessary and able.
- Evaluate the effectiveness of the approach in discerning the issues for training.
- Adjourn session after it is clear when the group will be reconvened.

Session 2 Humanistic Patient Care: Definitions and Components

Purposes of the Session

- To develop an operational definition of humanistic patient care for the group,
- To discuss the elements of humanistic patient care, and
- To identify areas of weakness or conflict in team performance in the provision of humanistic patient care.

Participant Preparation

- None

Trainer Preparation

- Review sections of the series: Monograph 3, Chapters I, II, III, IV, V; Monograph 3, Chapter VI.

- Review, if desired, the following recommended major written resources:

  - Beesterveey, S., "Staff Stress in a Newly-Developed Palliative Care Service," Canadian Psychiatric Association Journal, 22, 1977, pp. 387-392.
  - Halstead, L. and Halstead, B., "Chronic Illness and Humanism: Rehabilitation as a Model for Teaching Humanistic and Scientific Health Care", Archives of Physical and Medical Rehabilitation, 1977, February, 1978, pp. 83-87.
  - Howard, J. and Strauss, A. (eds.), Humanizing Health Care, N.Y., John Wiley and Sons, Inc., 1975.
  - International Work Group on Death, Dying and Bereavement, "Assumptions and Principles Underlying Standards for Terminal Care," American Journal of Nursing, February 1978, pp. 288-291.
  - Miller, D.C., "Professional Education for Humanistic Medicine," in Symposium of Humanistic Medicine, Human Of Al. Lake, San Francisco, Institute for Study of Humanistic Medicine, 1975, pp. 66-78.
  - Human, H. et al., The Hanuman Principle: The Feminine Principle and Humanistic Medicine, San Francisco, Institute for Study of Humanistic Medicine, 1975.

- **Select and reproduce for dissemination, handout** on definitions or components of humanistic patient care (see Examples from Hospice Training Experience).

(Estimated Time for Activity)	(Activity)
(10-20 Min.)	**Opening Remarks**
	• Introduce (if necessary) self and any other non-participants (e.g. recorder) to the group. (Length and nature of introduction and other opening remarks depend on how previous assessment session was and if conducted by self.)
	• Describe own role as facilitator and identify expectations for group. Identify person in charge and that person's role in the conduct of the training.
	• Review training outline decided upon in previous session.
	• Review session's purposes, agenda, and expected outcomes; ask for agreement from group.
	• Respond to any questions.
(130-140 Min.)	**Presentation and Discussion**
	• Provide a handout or slide presentation of definitions or interpretations of humanistic patient care as reflected in the humanistic medicine literature. Permit time for the reading of the handout (See Examples from Hospice Training Experience).
	• Facilitate discussion based on impressions of and reactions to the provided definitions.
	• Make brief presentation (10-20 minutes) on "Values, Attitudes, and Behavior" (see Examples from Hospice Training Experience) and the elements which influence the quality of the interrelationship of patients and care providers:
	○ Enhancing the relationship between health care providers and patients must first begin with dealing with the needs and the feelings of the care provider (frequently) related to working environment or organization).

(Estimated Time for Activity)

(Activity)

- Personal qualities (values, principles, and behaviors) of both persons and care providers affect the quality of the interpersonal relationship and the provision of humanistic patient care.
- Frequently there is a developmental gap between stated values, principles, and behavior (V/P/B) and the actualization of these. Differences may be unnoticed or acknowledged (congruent or incongruent as affected by factors, patterns, climate).

- "Developmental Gap" presents an opportunity to change things. An increased awareness of values, principles and behavior (V/P/B) incongruence with increased responsibility for individual decisions more investigations about self there is increased responsibility to explore incongruence in stated and actual values, principles and behavior.

- Discuss the positive and negative consequences of this increased awareness of the developmental gap.
- Facilitate discussion (in-depth account) of values, principles and behavior and how they influence the values, principles and behavior of others.

(10-15 Min.)

Closing Remarks

- Reinforce importance of self awareness in increasing one's responsiveness to others in the environment.
- Conduct evaluation of the session.
- Bring closure to the process.
- Confirm time and agenda for next session.

Session 3 — The Application of the Prospective Patient Care Approach

Purposes of the Session

- To further develop an operational definition of humanistic patient care for the group, and
- To look at specific applications in hospital care.

Participant Preparation

- None

Trainer Preparation

- Review sections of the manual: Monograph 2, Chapter III; Monograph 3, Chapter II.

- Review, if desired, the following recommended major written resources:
  - Erickson, P., Reinking, The Activities of Individual Pharmacists at Five Different Types of Hospitals, Minnesota Studies for Health Care Management, Minneapolis Hospital and Medical Center, 1979.
  - Hamer, R. et al., The Hennepin Experience, The Personnel Structure and Productivity Methods for Pharmacies, Improving the Utility of Pharmaceutical Services, 1975.

Participant Prep For Activity

Activity

(10-15 Min.)

Opening Remarks

- Review the purposes, agenda and expected outcomes for this session and ask for agreement from the participants.
- Provide an opportunity for participants to raise questions about the previous session and respond to those questions.

[illegible]

[illegible]

[illegible]

[illegible]

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- [illegible]
- [illegible]

[redacted]

[illegible]

(b) [illegible]

[illegible]

[illegible]

[illegible] Example of Presentation of Values, Principles and Behaviors

[illegible]

[illegible]

[illegible]

ultimately influence the behavior of others in the setting as well. Hospice staff who are sensitive and responsive to the needs of patients and families must also possess genuine positive regard for co-workers. A heightened awareness of the needs of others, and the ability to be responsive to those needs and supportive of the individual is a major element in the successful facilitation of humanistic patient care.

Figure adapted from: Training session flipchart drawing.

(d) Example of Handout Comparing "Scientific Medicine" to "Humanistic Medicine"*

A handout that might be useful as a basis for discussion in Session 3 is the following chart developed by Halstead and Halstead comparing "Scientific Medicine" and "Humanistic Medicine".

Halstead and Halstead describe humanistic medicine as a broad base of subjective, intuitive and empathic medical knowledge coupled with personal interaction and caring skills. They document how humanistic medicine pervades and optimizes many aspects of the medical interaction, and contrast the differential impacts of "scientific" and "humanistic" medicine in ten impact areas. Since in actual practice the comparison of scientific and humanistic medicine is not a dichotomy but rather is a matter of differences in emphasis along a continuum, the chart presented needs to be approached as an oversimplification constructed to identify these differences more clearly.

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* Halstead, L. and Halstead, K., "Chronic Illness and Humanism: Rehabilitation as a Model for Teaching Humanistic and Scientific Health Care", Archives of Physical and Medical Rehabilitation, 59:2, February 1978, pp. 57-61.

Scientific Medicine and Humanistic Medicine: A Comparison

Aspects of Medical Interaction	Scientific Medicine	Humanistic Medicine
Problem orientation	toward disease as biological event	toward illness as human event
Physician role	doer and knower	teacher
Patient role	passive and uninformed	active and informed
Physician/patient relationships	detached, reserved and impersonal	empathic and personal
Physician/health care team relationships	hierarchial and dominant	facilitative and egalitarian
Physician/physician relationships	competitive and isolating	supportive and collaborative
Therapeutic approach	treatment: to effect cure with technology	management: to effect relief
Physical setting	sterile	warm, homey
Care orientation	for convenience of staff	for convenience of patient
Objective	to cure: to enhance physiological function	to help: to enhance physical and psychological well-being

Source: Halstead, L. and Halstead, B., "Chronic Illness and Humanism: Rehabilitation as a Model for Teaching Humanistic and Scientific Health Care", Archives of Physical and Medical Rehabilitation, 59:2, February 1978, pp. 57-59.

(a) Example of Goal Statements for the Development of Humanistic Patient Care in the Hospice Setting

After having discussed definitions and components in the initial training session (and possibly one assessment session), participants are prepared to begin examining the application of humanistic patient care in their own hospice setting. The following are general goals for the development of humanistic patient care in a hospice setting. In Session 3, these goals might be considered as the trainer's starting point for a discussion with hospice staff about their own goals for training in humanistic patient care and how these goals are operationalized in the work setting.*

- To assist staff in the realization of patient/family as the unit of care. The people-oriented and patient-centered approach to care emphasizes the details of total care rather than solely the disease process. The participation of the patient and the family are encouraged with the patient serving as the teacher to family and staff, providing additional knowledge and insights about themselves. The emphasis on the patient remains within the context of the family and thus, family are encouraged to express individuality and maintain own idiosyncrasies. Patients are permitted to die as they lived, not according to a predetermined mold.

- To help staff appreciate that the emphasis on control of symptoms & psychological symptoms is primarily intended. Skilled medical care in the relief of symptoms and expert bedside nursing care are major emphases in hospice care. The patient will experience difficulty in exploring interpersonal issues and enjoying interpersonal relationships until such time as chronic pain, nausea, constipation, and other distressing symptoms of disease processes have been medically-managed. Physical systems designed to maintain bodily functions are discontinued in most instances as they do not contribute to the comfort of the patient. Primary concerns are comfort, mobility, participation and other quality of life indices.

- To bring a cohesiveness to the team so there can be a [illegible] focus on all patient needs without ignoring living care needs. With the recognition that the emphasis in hospice care is on the quality rather than quantity of the remaining life, the greatest possible sense of well-being and self-worth are encouraged.

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* All operational goal statements (underscored) are an adaptation of the National Hospice Organization Standards, Standards of a Hospice Program of Care, 4th Revision, February 1979.

As multiple disciplines are represented in the care plan to make assurances for quality, in the highlighting of emotional, spiritual, or other psychosocial needs, clinical care needs may become obscured. Generally, physical symptom relief occurs prior to any psychosocial interventions and thereafter team members continually reassess the situation to ensure that an appropriate care plan is responsive to the immediately presenting needs of the patient.

- To enable both home care and inpatient care teams to function as a continuum, there is always the ability to continue hospital patient care. The emphasis is the continuity of care throughout the course of changing needs. The patient is not abandoned whether at home or as an inpatient. Maintenance at home is supported by a interdisciplinary team with 24 hour 7 day a week staff availability. As an inpatient the staff is consistent, continuing the care of the patient. Frequent team meetings and patient care meetings contribute to the coordination of care with patient and family input welcome.

- To ensure that services are provided by an interdisciplinary approach in a holistic way. At the disease process continues, attention is directed to the treatment of the patient's distressing symptoms, self image and self confidence. In addition to available nursing and social work services, physical, occupational, speech, music, drama and recreational therapies are employed. Patient consideration of a number of opportunities are encouraged but not forced. Awareness and acceptance of "where patients are" rather than "where they should be". Interdisciplinary services are available in a manner which is judged to suit the patient's needs and wishes.

- To provide 24 hour, 7 day a week coverage ensuring that [illegible] is available to patients and families in their home at all times. It requires the patient team to reflect some control of a situation where the disease process and the stressful decline in their health is out of their control. Hospice staff are to be willingly available twenty-four hours a day, seven days a week. Home care staff, inpatient staff, and the various consultants and contributing agencies and organizations come together to create a finely tuned comprehensive program of care, being available sensitive, knowledgeable care at all times. Staff support and development, smart communication systems enable staff and volunteers to continue this work.

- To recognize volunteers as an integral part of the team [illegible] the [illegible] to the [illegible] of each of its patients. Presence of caring persons who empathetically recognize the terminal phase characterizes a dimension of humanistic patient care. Volunteers of all types are a major contribution to the care effort in both the home and the inpatient setting. Whether a volunteer offers medical, artistic, occupational, or communication and support skills, all bring with them unique talents, traditions, insights, and associations which offer patients, families, and staff an abundance of opportunities for growth. At a time in a patient's life when friends may find it difficult to be available, volunteers provide new opportunities for new and differing interpersonal relationships.

- To develop interpersonal and intrapersonal skills which [illegible] support [illegible] through the period of bereavement. In the past staff have often been frustrated in efforts in terminal care because terminal support of the patient has been relegated to clergy who are not always skilled in this work and not always welcomed by the patient. Team meetings, staff support systems, and continuing inservice education plans an important emphasis on the exploration of intrapersonal issues and development of interpersonal skills which enable the care provider to be available to patient and family at the time of death. Staff remain available to, and in contact with, the family after death, facilitating grief work and identifying any serious ongoing problems.

4. SELECTED REFERENCE MATERIALS FOR TRAINING, RESEARCH, CURRICULUM DEVELOPMENT AND IMPLEMENTATION, CONSULTATION AND APPLICATIONS

The following represent selected resources for use by trainers and participants. References are not bibliographic specific as they relate to humanistic patient care; rather, citations represent a selection from the "humanistic medicine" literature. Additional citations have been included from the literature which explore interpersonal awareness. These resources are in no way intended to be exhaustive in the field.

Blau, B., Belknap, M. and Grossman, R., Case Studies and Methods in Humanistic Medical Care. Esalen Institute Program, San Francisco, Institute for Study of Humanistic Medicine, 1976.

Gordon, D., "Curing Medicine and Caring Medicine", Humanistic Family Practice, 1:1, July 1976, pp. 119-124.

Halstead, L. and Halstead, M., "Chronic Illness and Humanistic Rehabilitation as a Model for Teaching Humanistic and Scientific Health Care", Archives of Physical and Mental Rehabilitation, 59:2, February 1978, pp. 57-67.

Howard J. and Strauss, A. (eds.), Humanizing Health Care. New York, John Wiley & Sons, Inc., 1975.

Jourard, S. and Berkowitz, R., How To Be Your Own Best Friend. New York, Ballantine, 1971.

Rogers, C., On Becoming A Person. Boston, Houghton Mifflin Co., 1961.

Rogers, J., "The Characteristics of a Helping Relationship", Personnel & Guidance Journal, 37, September 1958, pp. 6-16.

Samen, H. et al (eds.), Concepts of Humanistic Medicine. San Francisco, Institute for Study of Humanistic Medicine, 1976.

Samen, H. et al (eds.), The Exercise Principle, the Feeling Principle and Humanistic Medicine. San Francisco, Institute for Study of Humanistic Medicine, 1976.

B. PSYCHOSOCIAL VARIABLES IN WORKING WITH THE DYING PATIENT

An integral part of the patient care provider's training in hospice/patient care includes an increased understanding of the variables which have influenced the manner in which an individual has cried and which ultimately will influence the dying episode. This section addresses the presentation of these psychosocial variables in the following ways: background information for trainers providing among other things, a rationale for the incorporation of these variables in the training; a model outline of the proposed sessions; and some examples from the training experience including a sample presentation. This section of the training manual is intended to make the trainer aware of pertinent topic issues and provide some guidelines in the presentation of these issues.

1. BACKGROUND INFORMATION FOR TRAINERS

(a) Focus of Session on Psychosocial Variables

Having examined in previous sessions interpersonal and intrapersonal values, attitudes and behaviors, and their relation to hospice/patient care, we are now able to move to an exploration of those variables which impact the values, attitudes and behaviors of hospice patients/families. In accordance the adaptive or maladaptive processes employed by patients and families in response to the terminal illness process, accuracy of death, and hospice, it is incumbent upon care providers to have at hand the psychosocial issues for their behavior. The principles of hospice/patient care require an orientation to things that psychological, social, cultural, spiritual, and age related underlying which influence personal belief systems and circumstantial behavior.

The ability to meet the needs of patients and families in a timely, empathic fashion is an important aspect of hospice care. Responding to these needs requires direct interaction and action. A commitment to which is to be determined based upon the information available about patient/family. Though it is not feasible to be aware of everything about each patient/family encountered, a care provider can develop greater empathy by being more conscious of those aspects of "surviving behavior", that is, behavior which may be considered to being a member of a group which shares a commonality. These commonalities, or psychosocial variables, are the topics of this training session. In exercising the three areas to be addressed in the training is hospice/patient care (i.e., personal development, knowledge and understanding, skill development), it is with the topic of psychosocial variables that we have focused in the area of knowledge and understanding. A discussion of these variables is an important principle in the discussion of patient and family needs, the topic to be next addressed in training.

[illegible] Remote Reconnaissance by Drones (Cameo)

[illegible]

[illegible] Crowded Cramming and Behavior

[illegible]

and the achievement of the desired learning results.

In the "working" session outline provided, the major emphasis on the preparation of short presentations has been noted. Discussion was held on ways to improve the quality and number of these presentations. Frequently in connection with the general needs of the group being involved in a unit or theme session. Participants in previous workshops have found it helpful to have a small group of colleagues to work with in developing their presentations. For example, if a workshop is concerned with a particular community this particular group could prepare presentations on the resources and activities that have been developed in the community and discussed among the participants in relation to the objectives of the workshop. Members may further prepare in the session outline as mentioned, an overview of their presentation, so as to consider what the session should accomplish as individual contributions of a larger whole, with attention particularly to avoiding the duplication of facts and information in the discussion of subsequent persons' topic.

It is in the planning of sessions of presentations which precede a consultant's presentation, that there are opportunities for considerable variety and participation of persons attending a workshop. Such steps as should increase the usefulness and the educational contribution. It is suggested that consideration be given to the planning of certain sessions which would be devoted to exchanges of information and ideas among participants. This activity may be undertaken in an informal manner. It is considered that a planned session of this kind may be more effective if the participants are asked to prepare in advance a statement of their problems or questions which they regard as significant and which they propose further discussion.

2. [illegible]

One session outline is provided for this particular topic.

Session 1 Psychosocial Variables of Consideration in Working with the Dying Person

Purposes of the Session

- To explore the psychosocial variables: death, illness, dying, personal, and cultural and their impact upon the dying experience.
- To facilitate awareness of the importance of these variables in providing compassionate patient care, and
- To explore personal as well as professional issues and concerns related to working with dying patients and their psychosocial variables.

Instructional Procedures

- Role

Content Procedures

- Review sessions of the session. Reference 1, Chapters 12 and 13; Reference 2, Chapter 10.
- Review, if desired, the following individual major topics:

Psychosocial Aspects of Dying

(1) Kübler-Ross, E., "Stages in Dying: Acts 3, Acceptance," Psychiatric Aid for Clergy, in Kübler-Ross, E. (ed.), Death: The Final Stage of Growth, The University of Michigan Medical Center, pp. 63-67.

(2) Kübler-Ross, E., "Adult Personalities: Toward Understanding of the Dying Person", in Kübler-Ross, E. (ed.), Death: The Final Stage of Growth, The University of Michigan Medical Center, pp. 117-127.

Psychosocial Aspects of Illness

(1) Wahl, O. and Cox, J. "The Stigma of Physical Illness: An Overview", in Wahl, O. (ed.), Coping with Physical Illness, New York, Medical Media Publications, 1977, pp. 3-15.

(2) Sontag, S., The Medical Double, New York, Farar Straus, 1977.

[illegible]

[illegible]

[illegible]

[illegible]

[illegible]

[illegible]

(Estimated Time for Activity)

- Provide examples from several different cultural groups which reflect the relevance of culture in the humanistic approach to care.
  - Chinese - It is believed that evil spirits are present at the time of death;thus it is desirable not to have an ill person die at home; the house may become haunted*.
  - Native Americans - Suppression of strong feelings is common among the American Indian and thus high levels of physical pain and psychological discomfort may be tolerated without complaint**.
- Present some examples of how cultural background may have implications for the provision of humanistic patient care.
  - Pain control - the meaning of pain, the behavioral response to pain, and the expectation of how pain will be responded to by others are all influenced by cultural background. Some cultures regard pain in a stoic fashion, exercising great emotional control. Other cultures permit the emotional expression of pain without any expectation of supression***.
  - Inpatient care/Home care - the place where an individual chooses to be cared for may be influenced by cultural background. Whereas elderly Chinese still associate the hospital as the place to die* (to prevent the evil spirits from haunting the home should death occur there) the customs and beliefs of other cultures may dictate the place of care be nowhere other than the home.
  - Intergenerational/Cross-cultural issues - over the years the impact of a modern and mobil society has made it more difficult for individuals to maintain the cultural purity of many age old rituals.*

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* Kubler-Ross, E., "Death in Other Cultures", Cross, 11:3, 1974, pp. 20-22.

** Davitz, L., Sameshima, Y. and Davitz, J., "Suffering As Viewed In Six Different Cultures", American Journal of Nursing, 76, August, 1976, pp. 1296-1297.

*** Benoliel, J. and Crowley, D., The Pain In Pain: New Concepts, American Cancer Society Professional Education Publication, 1974.

(Estimated Time for Activity)

Some first generation Americans still subscribe to the folk customs of their European upbringing while children and grandchildren have been enculturated into "Americanism" and thus observe different rituals. Inter-marriages between various cultures and religions have brought about a whole new set of rituals which through the blending only resemble those of the former cultures' generations.

•• Bereavement - mourning is a cultural response to death. Styles of mourning vary according to culture, religion and background; the style changes with time*. In modern day society mourners are encouraged to quickly resume a state of normalcy though some cultural mourning practices are apparently beneficial to the well being and general mental health of the bereaved. Practices such as the Irish wake or the Jewish shiva**, or the various rituals of the Hispanic cultures*** permit an opportunity for a visible expression of emotions which bring needed support to the bereaved.

(10-23 Min.)

Discussion - Culture

- Solicit from the group other examples of how cultural background may influence the provision of humanistic patient care.
- Discuss how cultural stereotypes may have negative consequences in the care process. Solicit from the participants examples of how they discern the degree of cultural importance in attending to patient needs.
- Facilitate discussion of how care providers respond to cultural cues from patients and families. Discuss what occurs when the cues are mixed between patient and family (e.g., strong cultural observance cues from older generation family members; less importance placed on some cultural rituals by younger patient). Emphasize the use of process issues skills.

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* Koff, T., Hospice A Caring Community, Cambridge, Winthrop Publishers, 1980, p. 82.

** Feifel, H., New Meanings of Death, New York, McGraw-Hill, 1977.

*** Koff, T., Hospice A Caring Community, Cambridge, Winthrop Publishers, 1980, p. 83.

(Estimated Time for Activity)	(Activity)
(5-10 Min.)	Presentation - Psychosocial Implications of Spiritual Background*

- Explain briefly the importance of care providers understanding the ramifications that spiritual beliefs have on the provision of terminal care.
  - Some religious groups may deny the reality of discomfort - both spiritual and physical (Christian Scientists).
  - Some religious groups are supportive of general medical practices but exercise some restrictions such as all drugs unless absolutely necessary (Seventh Day Adventists).
- Outline in some detail, an example of how spiritual beliefs (representative of an organized or non-organized religion) may influence the behavior of a hospice patient/family. Or, provide several more brief examples of beliefs of diverse spiritual groups, indicating the implications for the provision of humanistic patient care when caring for patients subscribing to those beliefs.
  - Baptist - "God works through the doctor." Those who may believe in predestination may respond passively to any overtures of care.
  - Christian Scientist - "Disease is a human mental concept that can be dispelled by 'spiritual truth'". Response to any medical treatment depends upon how devote a believer the individual is.
  - Mormon - Strong believers may believe in "devine healing" through the "laying on of hands".
  - Muslim/Moslem - Near death the patient must confess sins and beg forgiveness in the presence of the family. The family is responsible for the cleansing and the preparation of the body.
  - Mennonite - Individual dignity and self-determination are highly valued; any medicine or treatment which is perceived to affect the individual's will or personality may not be tolerated.
  - Pentecostal - Illness may be considered divine punishment, or more frequently, ill-

*Presentation content and quotations based largely upon the article: Pumphrey, J., "Recognizing Your Patients' Spiritual Needs", Nursing, December, 1977, pp. 64-69.

(Estimated Time for Activity)

ness is considered "an intrusion of Satan". Atonement is the deliverance from sin and sickness.

- Unitarian/Universalist - Believe each individual has the right to own individual values. "God helps those who help themselves." Clergy may not be welcomed when individual choses to assume responsibility for self.

- Discuss briefly the relationship between clergy (the patient's individual choice as opposed to the "chaplain" who is a standing member of the hospice team) and care providers:
  - Consultations with clergy to obtain more information about patient's beliefs,
  - Requests for involvement of clergy, and
  - Assistance to clergy in aiding in their understanding of patient's condition.

(18-23 Min.)

Discussion - Spiritual

- Solicit from the participants, a distinction (if there is one) between "organized religious beliefs" and "spiritual beliefs". Discuss levels of comfort in response to each.

- Discuss ways in which patients/families may touch upon spiritual concerns or express conflicts, search for an understanding listener, or indicate an absence of spiritual beliefs.

- Facilitate discussion of how care providers respond to the above defined cues from patients/families when: (a) spiritual beliefs are similar to own; or (b) spiritual beliefs differ from own. Focus upon process issues/skills.

(5-10 Min.)

Closing Remarks

- Bring closure to the session; respond to any final, brief questions.

- Conduct evaluation of the session.

- Confirm the time and the agenda for the next meeting of the group.

3. EXAMPLES FROM HOSPICE TRAINING EXPERIENCE: PSYCHOSOCIAL VARIABLES IN WORKING WITH THE DYING PATIENT

The following examples touch on some of the specific comments made by trainers on the various topic areas covered and offer some random dialogue from the discussions with the participants. These examples are intended to provide trainers with some understanding of the depth and tone employed in presentations and discussions. Given the range of topics covered in this session, the opportunities are vast for the manner in which this session can be conducted. Any recorded comments of the trainers or participants found in the examples are not verbatim transcripts but are sufficiently accurate to convey the session's content.

(a) Example of Trainer's Opening Remarks

These remarks were made by a trainer to open a session relating to psychosocial variables.

> We began to examine in previous sessions the importance of values and attitudes in shaping the behavior of an individual. Our discussion today of psychosocial variables will further demonstrate the comprehensive influence which values and attitudes have on an individual's chosen lifestyle and presumably on how an individual choses to die. Before our discussion of needs assessment, which is next on the training schedule, it behooves us to learn more about some of the psychosocial variables which impact the dying event. It is perhaps most easy to begin with discussions of aging, illness, and dying because each of these variables is frequently compounded by circumstances which reinforce cultural and spiritual variables.
>
> There are a few theoretical points I'd like to convey to you for each of the variables - aging, illness, dying, cultural, and spiritual - but discussion is important so I'll be brief in my remarks. Following the presentation of each topic we'll have some discussion about the implications for humanistic patient care; how does that sound?

(b) Example of Brief Presentation on Psychosocial Aspects of Illness

This presentation on "illness" is fairly representative of the length of the other four brief presentations made during one session on variables. Depending on the needs of the group being trained, it may be appropriate to provide more or less theory or content for one or more of the topics.

In clinical studies examining behavior it is revealed that the person's beliefs about his health may be more significant than his actual health status as evaluated objectively. Findings from early health studies indicate a direct correlation in the way a person feels and the way he actually performs. A person suffering from a disease does not alter his self-concept or his behavior until he becomes aware of his disease.

Illness in modern times has been institutionalized as a social role. The work of Dr. Talcott Parsons describes a set of behavior expectations attached to the "sick role". Obviously of importance to hospice staff is your awareness of how each of us have become accustomed to assuming the "sick role" from time to time because these episodes are frequently not the roles which are aspired to in the hospice setting. Parsons lists four aspects of the institutionalized expectation system relative to the sick role.

- There is an expectation that the sick individual will be unable to fulfill his normal social responsibilities and, furthermore, that he should not try to fulfill them.

- It is assumed that the sick individual cannot make himself well by an act of the will and that his condition is such that he must be taken care of.

- Being ill is undesirable and the individual has an obligation to want to get well. (Because the patient refuses chemotherapy, everyone feels he is unconsciously not trying to get well.)

- The sick individual has an obligation to seek competent medical help, usually from a physician, and he has an obligation to cooperate with the physican so that he will regain his health.

Individuals are granted exceptions from normal activities and are deserving of help only if they communicate a desire to get well and seek help. This brings up once more the topic of congruence of behavior. Patients respond in direct correlation to how others expect them to respond. The health care system of this country has developed an effective mode for teaching people to be "good" patients. Though patients may conform to the expectations of the system it is unrealistic to believe that there is no stress associated with this conformity. The appearance of symptoms is always stressful for if individuals are unable to meet social responsibilities (be employed, be social), these symptoms will also be accompanied by fear and anxiety. Whether the symptoms represent impending death, personal degradation or last chances, they require a coping

strategy and this may cause personal and familial anguish. In short, the implications of anyone getting sick are not confined to that individual but ramify throughout the social networks in which he is engaged. Because of this, they not only disrupt our own ability to function but they also disrupt organized activity and relationships in the family - everyone in the whole constellation of the patient's family.

(c) Example of Trainer's Remarks Relating to Conditions Facilitating an "Appropriate Death"

These remarks were made as closing comments during a presentation on psychosocial aspects of dying.

There are three factors that seem to be paramount in helping people to die in a fashion they want to call an appropriate death.

- A warm and intimate relationship, preferably with a family member or friend, but, if necessary, a care giver,
- An open awareness in which the dying person and the important people in his social environment are aware of the prognosis and can relate to each other in terms of the terminal condition, and
- A belief system that provides for meaning.

In regards to this third point on a belief system, I'm familiar with a hospice which had a senior medical student call from Tufts; he wanted to know if he could come to hospice. He was a terribly nice young man. The hospice had a Lutheran chaplain, a Sister of St. Joseph for an administrator and a chapel - the student was very comfortable with it all but he felt he needed to make it known that he was an atheist. He participated in every social activity the hospice had and he was always there because he didn't want to miss anything. He would have the physicians call him on night calls - he was totally involved and a very caring person. Two months after he was there, hospice staff noticed him sitting in the chapel. The chapel was more of a quiet sitting room than a strictly denominational chapel. A week later he talked to the medical director and told him he had an awful lot of work to do when he got home. He said that he had had the privilege of being with so many patients when they died and there had never been a time when he felt the patient and he had been alone at the time of death. He said he would have to go home and work out the meaning of all this. Spirituality need not be defined, it comes through in a lot of forms and a lot of languages.

4. SELECTED RESOURCE MATERIALS FOR TRAINING: PSYCHOSOCIAL VARIABLES IN WORKING WITH THE DYING PATIENT

This section offers selected resources for use by trainers and participants. The topical bibliographies are in no way all inclusive, nor are they intended to be. The majority of the references have been selected based on their practical utility to care providers and for the content or instructional purposes of trainers. Some "landmark" references of a more philosophical yet thought-provoking nature have been cited given the emphasis throughout training on intrapersonal awareness. Other seemingly "landmark" references have been omitted because the occupational familiarity of hospice staff warrants a more sophisticated treatment of the topics. All citations appear alphabetically within each of the five topic areas. Topic areas appear in the order in which they were addressed in the sample session outline.

Psychosocial Aspects of Aging

Anderson, W., Practical Management of the Elderly, Oxford, England, Blackwell Scientific Publications, 1971.

Berezin, M., "A Partial Grief for the Aged and Their Families", in Pattison, E. (ed.), The Experience of Dying, Englewood Cliffs, Prentice-Hall, 1977, pp. 279-286.

Birren, J., and Schaie, K. (eds.), Handbook of the Psychology of Aging, New York, Van Nostrand Reinhold Co., 1977.

Kane, R.A., Consequential Decisions of Older Persons: A Framework for Study, Santa Monica, The Rand Corporation, p-6233, 1978.

Neugarten, B., "Adult Personality: Toward a Psychology of the Life Cycle", in Neugarten, B. (ed.), Middle Age & Aging, Chicago, The University of Chicago Press, 1975, pp. 137-147.

Neugarten, B., "Editor's Note: Erik H. Erikson: Generativity and Ego Integrity", in Neugarten, B., (ed.), Middle Age and Aging, Chicago, The University of Chicago Press, 1975, pp. 85-87.

Palmore, E. (ed.), Normal Aging: Reports From the Duke Longitudal Study, 1955-1969, Durham, Duke University Press, 1970.

Palmore, E. (ed.), Normal Aging II: Reports From The Duke Longitudinal Study, 1970-1973, Durham, Duke University Press, 1974.

Peck, R., "Psychological Development in the Second Half of Life", in Neugarten, B. (ed.), Middle Age and Aging, Chicago, The University of Chicago Press, 1975, pp. 88-92.

Seligman, M., Helplessness: On Depression, Development and Death, San Francisco, W. H. Freeman and Company, 1975.

Stevens, C., Special Needs of Long Term Patients, Philadelphia, J.B. Lippincott Co., 1974.

Psychosocial Aspects of Illness

Crary, W. and Crary, G., "Emotional Crisis and Cancer", Ca - A Cancer Journal for Clinicians, 24:1, January-February, 1974, pp. 36-39.

Gordon, G., Role Theory and Illness: A Sociological Perspective, New Haven, College & University Press, 1966.

Holland, J.C., "Psychologic Aspects of Cancer", in Holland, J. F. and Frei, E., III (eds.), Cancer Medicine, Philadelphia, Lea & Febiger, 1973, pp. 991-1021.

Miller, C., Denner, P. and Richardson, V., "Assisting the Psychosocial Problems of Cancer Patients: A Review of Current Research", International Journal of Nursing Students, 13, 1976, pp. 161-166.

Moos, R. and Tsu, V., "The Crisis of Physical Illness: An Overview", in Moos, R. (ed.), Coping with Physical Illness, New York, Plenum Medical Book Company, 1977, pp. 3-21.

Parsons, T., The Social System, New York, Free Press, 1951.

Schnaper, N., "Psychosocial Aspects of Management of the Patient with Cancer", Medical Clinics of North America, 61:5, September 1977, pp. 1147-1155.

Twaddle, A., "The Concepts of the Sick Role and Illness Behavior", Advanced Psychosomatic Medicine, 8, 1972, pp. 162-179.

Zola, I., "Illness Behavior in the Working Class: Implications and Recommendations", in Shostak, A. and Gomberg, W. (eds.), Blue Collar World: Studies of the American Worker, Englewood Cliffs, Prentice-Hall, 1964.

Psychosocial Aspects of Dying

Feifel, H., New Meanings of Death, New York, McGraw-Hill, Inc., 1977.

Feifel, H., "The Taboo on Death", American Behavioral Science, 6, 1963, p. 66.

Fulton, R., "Death and Dying: Some Sociological Aspects of Terminal Care", Modern Medicine, May 29, 1972, pp. 74-77.

Fulton, R., Death and Identity, New York, John Wiley & Sons, 1974.

Garfield, C. (ed.), Psychosocial Care of the Dying Patient, New York, McGraw-Hill Book Co., 1978.

Harper, B., Death: The Coping Mechanism of the Health Professional, Greenville, SC, Southeastern University Press, 1977.

Kastenbaum, R. and Aisenberg, R., The Psychology of Death, New York, Springer Publishing Company, 1972.

McCorkle, R., "The Advanced Cancer Patient: How He Will Live - And Die", Nursing, October 1976, pp. 46-49.

Pattison, E., The Experience of Dying, Englewood Cliffs, NJ, Prentice-Hall, 1977.

Reynolds, D. and Kalish, R., "The Social Ecology of Dying: Observations of Wards for the Terminally Ill", Hospitals and Community Psychiatry, 25, 1974, pp. 147-152.

Psychosocial Implications of Cultural Background

Bullough, B. and Bullough, V., Poverty, Ethnic Identity and Health Care, New York, Appleton-Century-Crofts, 1972.

Davitz, L., Sameshina, Y. and Davitz, J., "Suffering as Viewed in Six Different Cultures", American Journal of Nursing, 76, August 1976, pp. 1296-1297.

Graham, S., "Socio-Economic States, Illness and the Use of Medical Services", Milbank Memorial Fund Quarterly, 35, 1957, p. 58.

Loudell, F., "Folk Medical Beliefs and Their Implications for Care of Patients", Annals of Internal Medicine, 81, 1974, p. 82.

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Suchman, E., "Social Patterns of Illness and Medical Care", Journal of Health and Human Behavior, 6:2, Spring 1965.

Wolff, B. and Langley, S., "Cultural Factors and the Response to Pain: A Review", American Anthropology, 70, 1968, p. 494.

Zborowski, M., "Cultural Components in Responses to Pain", Journal of Social Issues, 8, 1952, p. 16.

Zola, I., "Culture and Symptoms - An Analysis of Patients' Presenting Complaints", American Sociological Review, 31, October 1966.

Psychosocial Implications of Spiritual Background

Dawson, J., The Cancer Patient, Minneapolis, Augsburg Publishing House, 1978.

Frankl, V., Man's Search for Meaning, New York, Pocket Books, 1963.

Jacobs, W., The Pastor and the Patient, New York, Paulist Press, 1973.

Kavanaugh, R., Facing Death, Baltimore, Penguin Books, 1972.

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Pumphrey, J., "Recognizing Your Patients' Spiritual Needs", Nursing, December 1977, pp. 64-69.

Reeves, R.; "Professionalism and Compassion in the Care of the Dying", Pastoral Psychology, November 1971, pp. 7-14.

Reynolds, R. and Waugh, E. (eds.), Religious Encounters with Death, University Park, The Pennsylvania State University Press, 1977.

Schilling, S., God and Human Anguish, Nashville, Abingdon, 1977.

Swift, J., "The Chaplain's Role in Care for the Dying: Toward a New Understanding", Canadian Medical Association Journal, 115, 1976, p. 181.

Taylor, M. (ed.), The Mystery of Suffering and Death, New York, Image Books - Doubleday and Co., Inc., 1974.

C. PATIENT AND FAMILY NEEDS, ENVIRONMENT AND RIGHTS

The preparation of the hospice care provider would not be complete without a discussion of patient/family needs. This includes: consideration of the important data required in assessing the needs of hospice patients/families; an investigation of how that data is obtained and utilized and the implications that these practices have on both those receiving care and those providing care; and the crucial part that patients' rights and the patient care environment play in the provision of humanistic patient care. As hospice care providers endeavor to provide psychosocial and spiritual support to every hospice patient/family, they recognize that time, expertise, and a multitude of presenting patient/family problems can limit their ability to lend support. Because there is no single "right" approach for caring, a further exploration of what works well for individuals and the team as a unit is warranted. This section addresses the following topics in three sessions: factors which influence understanding patient and family needs, identifying and prioritizing patient and family needs, and the patient care environment and patient rights. The following information on the sessions is intended to guide the trainer(s) by bringing relevant issues to light based upon demonstrated experience.

1. BACKGROUND INFORMATION FOR TRAINERS

(a) Timing and Number of Sessions

Having previously examined care providers' personal values and views about humanistic patient care and learned more about the many diverse variables which shape both care providers and the patients/families they care for, we are now prepared to explore further the important interrelatedness of this knowledge and expanded awareness. The important first step of recognizing personal needs, and potential barriers to having these needs met, whether in wellness or sickness, provides the foundation for a discussion of the many factors which influence the identification of the needs of patients/families. An experiential exploration of personal needs facilitates the understanding of personal needs of others. The bridge between a conceptual understanding of needs and the accessing of the data which confirms and prioritizes the needs represents a difficult process which is stress inducing for individual care providers and the team as a whole. For purposes of this training effort these two very related topics have been addressed in two separate sessions, three hours in length each. The natural sequence of the two topics - factors which influence an understanding of needs, first; identifying and prioritizing needs, second - is both obvious and recommended. Sufficient time is to be made available to explore each topic so that an appreciation may be gained for both what is desirable (optimal) in addressing patient/family needs, and what is achievable (practical) in meeting those defined needs based upon the limitations imposed by time and the availability of resources.

Conceivably, if training time is limited, these two topics could be addressed in one session, four hours in duration. Session 6, identifying and prioritizing needs, affords a hospice an excellent opportunity to re-examine its own assessment forms and possibly restructure them.

The third session (Session 7) in this segment of the training program addresses patients' rights and the patient care environment. Though these topics are important regardless of where the patient is being cared for, they take on additional importance when the hospice has inpatient beds. Patients cared for in the home may enjoy more liberty and control whereas placement in an institutional setting often jeopardizes that sense of control and lessens the sureness of what constitutes "acceptable behavior". While the discussions inspired by the topic of patients' rights encourage the continual exploration of issues in humanistic patient care, the legal facets of this topic are of greater relevance to those hospice programs which currently offer, or anticipate offering, inpatient care. Similarly, discussions of the patient care environment are inherently important given an interpretation of "environment" which connotes the multifaceted aspects of environment (i.e. physical, emotional, attitudinal), but may have still greater significance when an inpatient unit is the "environment" in question. Trainers should not only be aware of whether a hospice program offers inpatient care, but also know something of the ambiance of that environment and emphasize specific issues in training based upon that knowledge (e.g. any state law pertaining to maintenance of patients' rights in institutional environments).

It is not to be assumed by the trainer that because a hospice does not have an inpatient unit that there is little need for the topics addressed in Session 7. The deletion or combination of any one or more of the sessions is to be mutually determined by hospice administrator and trainer based upon individual hospice need and available time and resources. The topic of patient care environment and, to a lesser degree, the topic of patients' rights may lend themselves quite comfortably to a more abbreviated treatment in conjunction with other topics addressed elsewhere in the training (e.g. one of the sessions on definitions and applications of humanistic patient care or a session on patient/staff relationships).

(b) Session Relatedness to Process Issues

The principal thrust of the didactic and experiential training conducted in these sessions is that of interpersonal awareness. The topics explored touch upon all of the other defined process issues/skills though probably most notably and substantially the issue of listening. The materials offer a great many implications for stress management by the care giver and, depending upon the special emphasis placed upon this issue by a trainer, it may become a major issue of endeavor in the conduct of training for this collection of sessions. The

introduction of topics on patient and family needs, assessment issues, patients' rights and the patient care environment encourages and permits the opportunity for an empathic awareness while continuing to reinforce the intrapersonal awareness. By participants exploring first the "people and things" of personal value to themselves, an increased understanding of those "people and things" of importance to others results. Through experiential exchanges participants will continue to find it necessary to confront conflicts in personal values and preferences thereby facilitating an increased understanding of own and team members' beliefs and motives, enabling the recognition and acceptance of differences in fellow care providers, patients and/or families.

(c) Trainer Planning of Session

The nature of the planning necessary for the presentation of these training topics varies according to the decision to address the topics in one, two, or three distinct and separate sessions. If time is at a premium there is the opportunity for the trainer, with some degree of ease, to address the topics in Sessions 5 and 6 in one training meeting of longer duration (recommend four hours). This would principally be accomplished by having participants complete the written exercises (appearing in Session 5), prior to the convening of the participants for training. The products (lists) from Exercise III could be edited and prepared either before or after the session so long as the activity is completed with all participants providing input. Processing time for all exercises must still be available to participants, however.

As was indicated earlier, Session 7 could be adapted to permit discussion of those topics and issues in conjunction with the topics of other sessions elsewhere in the training program. This would require condensing the amount of time allotted for activities in the selected sessions and planning with sufficient lead time to ensure a thorough course of training and preclude any inadvertent omissions.

In the event that the topic areas for this portion of the training are addressed in three separate sessions as has been outlined, then planning for each topic is less complex. After the relevant sections of the appropriate monographs have been received and any necessary additional reading completed, the trainer needs only to identify a suitable case study for the exercise described in Session 6. Assistance might be sought from the hospice administrator in locating a case indicative of the multiple, complex, often conflicting needs which overtly or covertly become evident as a hospice care provider works against the clock with patient/family. The more complex the circumstances and problems within the case, the more beneficial the assessing and prioritizing exercise will be.

(d) Trainer Behavior in Sessions

Factors which influence understanding patient/family needs, Session 5, quite naturally lends itself to an experiential format. The exercises included in this session outline proved to be quite effective in establishing a sensitive work environment for completion of the empathic "needs lists". Sessions 6 and 7, however, are less inclined toward an experiential treatment and there may be the subtle tendency to become too didactic, entertaining a lecture-type format. This is not the intent. For optimal success in the meaningful completion of these two sessions, the trainer must demonstrate a forte in bringing conceptual ideas to a group and facilitating the application of those concepts within the immediate work experience of participants. As staff stress may become apparent during discussions of prioritizing needs, and patients' rights versus the rights of others (including the care provider), the trainer should be prepared to deal with these issues in a supportive fashion as they relate to the content areas being discussed. Staff stress issues will become evident in the next couple of sessions as well and the trainer should be cognizant of the need to apportion time for discussions of stress (relating to the immediate training areas) accordingly.

Session 6, identifying and prioritizing patient and family needs, follows a highly experiential session while it has only one exercise. To maintain the established high level involvement of group participants it is necessary that "presentation and discussion" portions of the session be just that - with emphasis upon discussion. Issues have been offered within the outline as a guide to the trainer as to what to expect from the group. Participants are to do most of the work during those periods with the trainer performing a "gate keeping" function to ensure keeping participants on track. It is not necessary that every issue identified in the outline be conveyed. The principal theme is humanistic patient care for the hospice patient/family. Similarly, in a less specific discussion of "assessment", the emphasis is upon the processing of feelings of inadequacy in meeting patient/family needs, once identified, and other inherent difficulties related to assessment.

The session on patient care environment and patients' rights, Session 7, may easily become too didactic if it is the intent of the trainer to focus upon physical environments and written laws and legislation. Relevant federal or state laws may be best utilized as a handout with a minimal amount of time spent on a thorough review of the material. A more meaningful use of time as related to humanistic patient care would be an exploration of care providers' practices in the adapting of physical environments for the maintenance of patient independence in the home (i.e. congruence between stated values and actual behavior); or the identification of conflicting issues in the maintenance of patients' rights (e.g. patient/staff value conflicts which may compromise the "humanism" in the provision of patient care). A discussion of the "appropriateness" of patient care environments also lends itself to the

appearance of value conflicts and the trainer should be prepared to support participants in working through these conflicts. The success of this session relies upon the trainer maintaining the active involvement of all participants within their level of comfort.

2. OUTLINE OF TRAINING: PATIENT AND FAMILY NEEDS, ENVIRONMENT AND RIGHTS

Outlined within this section are three sessions, one each dealing with the topics of understanding patient and family needs, the identification and prioritization of those needs, and the patient care environment and patient rights. The outlines represent illustrative demonstrations of how the sessions were conducted in the training experience and are by no means intended to dictate a "boiler plate" for subsequent training experiences. Trainers are expected to modify these session outlines to reflect the needs of a particular hospice group.

Session 5 Factors Which Influence Understanding Patient and Family Needs

Purposes of the Session

- To identify factors which will facilitate a better understanding of patient/family needs, and
- To develop inventories of "things to know" about patients, families and patient/family units.

Participant Preparation

- (Optional - depending upon time constraints) Complete exercises prior to session. Each participant is to bring completed exercises with them to session for discussion.

Trainer Preparation

- Review sections of the series: Monograph 2, Chapters II, IV; Monograph 3, Chapter VI.
- Review, if desired, the following recommended major written resources:
  - Koff, T., "The Hospice Environment", in Hospice A Caring Community, Cambridge, Winthrop Publishers, 1980, pp. 123-134.
  - Margolis, J., "Conceptual Aspects of a Patients' Bill of Rights", Connecticut Medical, Vol. 39, September 1975, pp. 582-587.
  - Paulen, A., "Living with Cancer: The Rights of the Patient and the Rights of the Nurse", in Peterson, B. and Kellogg, C. (eds.), Current Practice in Oncologic Nursing, Vol. I, St. Louis, C.V. Mosby Co., 1976.

(Estimated Time for Activity)	(Activity)
	Opening Remarks
(5-10 Min.)	• Review the purposes, agenda and expected outcomes for this session and ask for agreement from participants. • Provide an opportunity for participants to raise questions about the previous session and respond to those. • Offer rationale for session topic and next several sessions (see Examples from Hospice Training Experience).
	Exercise I*
(10-15 Min.)	• Introduce the exercise with a statement which reflects the need for care providers to examine their own needs in order to enable a clearer distinction between personal needs and patient and/or family needs during assessment. • Distribute the written exercise with the following instructions and comments: •• Throughout the exercise two opposing statements about the same topic are made with a line running between them. The line represents the continuum of all possible views about the topic. •• For each set of paired statements, place a mark on the line which describes where <u>your</u> (care provider's) views on the subject fit on the line. Mark each topic to reflect personal views as closely and as accurately as possible. •• Wherever in the exercise the word "nurse" appears, substitute "caring person" if discipline is other than a nurse. •• The exercise is to be confidential within the group. • Permit sufficient time for the completion of the written exercise.
(40-50 Min.)	**Exercise I - Discussion** • State that participation in discussion should

* <u>Exercise I</u> found in Examples from Hospice Training Experience. Source: Hardin, K. and Slater, V., <u>Experimental Exercises on Death and Dying</u>, Salt Lake City, University of Utah College of Nursing, 197

(Estimated Time for Activity)

be at the level of comfortable involvement for each individual.

- Discuss selected sets of paired statements taking the following into consideration:
  - Where do individuals place themselves on the continuum? Is there a consensus of agreement with everyone in the group or are views quite different?
  - What factors helped individuals decide where to place their marks? Was it easy or difficult to decide what personal views were?
  - How does personal belief about the statement affect the quality of care each individual gives to patients and their families?
  - Are personal beliefs consistent with practices in the current work setting?

Exercise II*

(5-10 Min.)

- Introduce the exercise by way of acknowledging the outcome of the previous exercise.
  - The opportunity has been provided for care providers to become more aware of personal values which may influence the recognition or creation of needs in a patient/family assessment.
  - Having examined personal values there is now the opportunity for care providers to explore additional facets of their own personalities, enabling a still greater understanding of the complexities of patient/family needs and clues for responding to these needs through the provision of humanistic patient care.
- Distribute the written exercise with the following comments and instructions:

* Exercise II found in Examples from Hospice Experience, Source: Hardin, K and Slater, V., Experiential Exercises on Death and Dying, Salt Lake City, University of Utah College of Nursing, 1978.

(Estimated Time for Activity)	(Activity)
	◦◦ Information from personal charts does not have to be revealed; the exercise is confidential. ◦◦ There are four questions asked; respond to each question with one, best possible answer.
	• Permit time for completion of the written exercise.
	Exercise II - Discussion
(30-40 Min.)	• Request discussion of a conceptual perspective based on personal responses. (Individual responses, e.g., names, need not be shared).
	• Discuss the value of the question "Who will be at your bedside when you die?" with the following types of facilitating questions: ◦◦ Are there any health care professionals (doctors, nurses, social workers)? ◦◦ Who is at the bedside of patients you work with when they die? ◦◦ Do you believe the patients would like their family members there?
	• Discuss the value of the question "What is your greatest strength?" with the following types of facilitating questions: ◦◦ If you were dying, how would your strength help you? ◦◦ Think of some patients you have worked with. What, and/or who, was their greatest strength? How did it help them?
	• Discuss the value of the question "What is your greatest accomplishment?" with the following types of facilitating questions: ◦◦ If you were dying, would you be comfortable talking with someone who wanted to discuss this accomplishment? Why? Why not? ◦◦ Think of a patient you have or have had. Do you know what he sees as his greatest accomplishment? How did you, or can you, find out what it is?
	• Discuss the value of the question "What do you

(Estimated Time for Activity)	(Activity)
	want placed on your tombstone?" with the following type of facilitating question: •• How does your epitaph relate to your greatest accomplishment and strength?
	Exercise III*
(35-45 Min.)	• Introduce the exercise by way of acknowledging the outcome of the previous two exercises. Prepare to develop three separate lists identifying the kinds of information needed for patients, families and patient/family units, to become enlightened about the dimensions or degrees of their needs. • Develop a list entitled "Ideal list of things to know about the patient". List on a blackboard/flipchart all suggestions made of the kinds of patient information to be collected in an assessment which would better enable the delivery of humanistic patient care. • Develop a second list entitled "Ideal list of things to know about the family". List these suggestions on the blackboard/flipchart in such a way that both lists are visible simultaneously. • Develop a third list entitled "Ideal list of things to know about the patient/family unit". This list should also appear proximate to the other two lists. • Bring closure to the exercise after requesting last minute additions to any of the three lists.
	Closing Remarks
(5-10 Min.)	• Request all three lists be edited, typed, and duplicated for dissemination for next session on assessment. • Facilitate evaluation of day's session. • Respond to any further inquiries or comments.

* Exercise III introductory comments and exercise products from one hospice found in Examples from Hospice Training Experience (c).

Session 6 Identifying and Prioritizing Patient and Family Needs

Purposes of the Session

- To examine approaches to multidisciplinary patient/family needs assessment (i.e., how information is obtained),
- To explain the prioritization issues associated with a multidisciplinary needs assessment, and
- To study the benefits of problem-oriented charting in the provision of humanistic patient care.

Participant Preparation

- Finalize the lists created in the previous session on "things to know" about patient, family, and patient/family unit. Each participant should have a copy of these lists for this session.

Trainer Preparation

- Review sections of the series: Monograph 2, Chapter IV; Monograph 4, Chapter V.

- Review, if desired, the following recommended major written resources:
  - Kaplan, D., Grobstein, R. and Smith, A., "Predicting the Impact of Severe Illness in Families", Health and Social Work, 1:3, August 1976, pp. 72-82.
  - Payne, E. and Krant, M., "The Psychosocial Aspects of Advanced Cancer: Teaching Simple Interviewing Techniques and Record Keeping", Journal of the American Medical Association, 210:7, November 17, 1969, pp. 1238-1242.
  - Schell, P. and Campbell, A., "POMR-Not Just Another Way to Chart", Nursing Outlook, 20:8, August 1972, pp. 510-514.

- Obtain an actual case study from one care provider receiving training. Have the study written up, reproduced, and ready for dissemination during a session exercise. Enlist the support of the care provider in responding (during the exercise) to questions anyone may have about the patient/family.

(Estimated Time for Activity)	(Activity)
	Opening Remarks
(5-10 Min.)	• Review the purposes, agenda and expected outcomes for this session and ask for agreement from participants. • Review the previous session and respond briefly to questions.
(90-100 Min.)	Presentation and Discussion
	• Review briefly (5-10 minutes) the lists developed in the previous session. Identify the merits of developing such lists, such as: •• Renews awareness of multitude of variables to be assessed, •• Provides insight into the kinds of beneficial information which should be shared between team members, and •• Offers guidance in the evaluation of instruments and tools currently used to gather patient/family information. • Discuss the difficulties and frequent obstacles to conducting a thorough patient/family needs assessment upon which a patient care plan can be created. With participants, identify major issues impacting the validity of an assessment; issues such as: •• Rapidly changing needs of patient/family, •• Patients'/families' congruence between behavior and reported needs/perceived feelings/actual experience (e.g. reported pain levels may be incongruent with actual pain; reporting behavior is influenced by cultural background), •• Physiological vs. psychosocial and spiritual needs - prioritization, and •• Patient care staff's comfort in obtaining sensitive information. • Facilitate discussion (10-15 minutes) of staff stress given the myriad of pressures inherent in the assessment process: •• Continual need for reassessment. •• Variations given the place of care - home or inpatient. •• Identification of family needs for bereavement care while simultaneously

(Estimated Time for Activity)	(Activity)

meeting current needs,
- Staff feelings of guilt and inadequacy due to inability to meet all needs (time constraints, lack of resources, etc.), and
- Patient/family involvement in patient care plan development (conflict in values, goals for care, etc.).

- Provide reassurance and support for continued commitment to assessment and development of care plans which reflect the goals and desires of the patient and/or family.

- Identify qualities which contribute to making assessment a humanistic practice:
  - Determine symptoms of concern to patient/family, acknowledge these.
  - Assess patient/family needs through body language, personal background, gestures, voice tones, symbolism, emotional states.
  - Convey genuine interest and caring to patient/family to better enable the critical sharing necessary for assessment.
  - Prioritize according to patient comfort, goals and desires.

- Discuss the merits and limitations of verbal communication (i.e. oral interview techniques) and identify other ways of conducting an ongoing assessment (20-30 minutes) such as:
  - While providing patient care (i.e. tenderness to touch or motion, despondency),
  - "Casual" conversations with patient and/or family,
  - Informal/formal team conferences involving patient and/or family,
  - Exchange of information with other care providers on the team, and
  - Utilization of problem-oriented charting.

- Examine the humanistic benefits of problem-oriented charting when utilized as an ongoing means of assessment:
  - Reflects the "problems" as reported by patient/family,

(Estimated Time for Activity)	(Activity)
	•• Enables a systematic way of re-assessing on-going problems and identifying new ones, •• Coordinates communication between care giving disciplines and enhances the function of the team, •• Supports care providers in problem solving and decision making, •• Assists in prioritizing based on input from all team members, •• Stimulates staff motivation and satisfaction with evidence of problem resolution or containment, and •• Benefits patient and family to see progress can be attained.
(50-60 Min.)	Exercise and Discussion • Disseminate copies of the prepared case study; have participants read it and ask clarifying questions in a manner similar to case conference. (Group questions are to be responded to by the care provider most knowledgeable about that aspect of the patient/family being discussed). • Assess the needs of the patient and family in question based on the information obtained in simulated case conference. •• Identify gaps in the information provided necessary to make a "valid" assessment. •• Identify techniques for obtaining the missing data which would contribute to further delineation of the needs. •• Prioritize the needs based on patient/family goals and desires. • Discuss the difficulties of the assessment exercise and the feelings experienced by participants.
(5-10 Min.)	Closing Remarks • Acknowledge once more the inherent difficulties in assessment of the terminally ill patient and family.

(Estimated Time for Activity)	(Activity)
	◆◆ Offer reassurance and encouragement to patient care staff. ◆◆ Emphasize the need for prioritization and involvement of the patient/family in the development of the care plan based on the identified needs.
	• Faciliate evaluation of the session.
	• Respond to final comments or inquiries and confirm time of next session.

Session 7 The Patient Care Environment and Patient Rights

Purposes of the Session

- To increase staff awareness of physical and social factors within the patient care environment which dictate lifestyle and impact the provision of humanistic patient care,
- To familiarize staff with the requirements of Federal rules and regulations related to patients' rights, and
- To identify conflicting issues in the maintenance of patients' rights and explore strategies for respecting, protecting and advocating those rights.

Participant Preparation

- None

Trainer Preparation

- Review sections of the series: Monograph 2, Chapter II; Monograph 3, Chapter IV; Monograph 4, Chapters IV, V.
- Review, if desired, the following major written resources:
  - Annas, G., "Rights of the Terminally Ill Patient", Journal of Nursing Administration, March-April 1974, p. 40.
  - Hillhaven Foundation, Training Manual for a Program of Understanding the Intent of Patient's Rights, Tacoma, Hillhaven Foundation, 1978.
  - Margolis, J., "Conceptual Aspects of a Patients' Bill of Rights", Connecticut Medical, Vol. 39, September 1975, pp. 582-587.
  - Ramsden, E., "Patients' Right to Know, Implications for Interpersonal Communications Process", Physical Therapy, 55:2, February 1975, pp. 133-138.
- Select and reproduce for dissemination any handouts for the group. (see Examples from Hospice Training Experience)

(Estimated Time for Activity)	(Activity)
(5-10 Min.)	Opening Remarks

- Review briefly the previous session; state its relatedness to day's topics.
- Review the purposes, agenda, and expected outcomes of this session and request group agreement.
- Respond to any questions.

(10-15 Min.) Presentation and Discussion

- Present brief remarks about the importance of the physical and social environment in the humanistic care of the terminally ill patient.
  - Physical environs - Whether the physical space surrounding a patient is that of a home or an inpatient unit, the space should be representative of the goals strived for in the overall mission of hospice - providing for the physical comfort and security of the patient in the setting of its chosing which permits the continuance of quality living and better enables the patient's maintenance of control.*
  - Social environs - Traditionally the family has been viewed as the primary source of support for the dying patient. The social environment should permit opportunities for the desired social interaction, degrees of familial involvement/detachment, and expressions of intimacy. Opportunities for the desired privacy (not to be mistaken for isolation) should also be available to the patient.**
- Facilitate discussion of the interrelatedness of these environmental variables with patient needs and the goals of hospice care.

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* Koff, T., Hospice a Caring Community, Winthrop Publishers, Cambridge, MA,1980, pp. 123-134.

** Ibid.

(Estimated Time for Activity)	(Activity)
	Exercise
(50-60 Min.)	• List on a flipchart/blackboard, those considerations deemed important by participants in assessing the "appropriateness" of a patient's physical environment. The following kinds of considerations are pertinent: •• Does the setting have homelike, livable characteristics? •• Is the environment suitable for, or adaptable to, the reduced energy levels or limited mobility of the patient? •• Does the space offer sufficient room for the comfortable/tolerable co-existence of all persons sharing the space? (Enough room to permit frequent visits by groups of people if this is desired by the patient?) •• Does the patient exhibit a sense of control and comfort within the environment? • Facilitate a discussion of (5-10 minutes) of how staff and patient and/or family values may conflict in the determination of the "appropriateness" of a patient's selected care setting. Solicit from participants when a physical environment (e.g., a patient's home) is <u>inappropriate</u> or <u>unsuitable</u> for the provision of humanistic patient care. Examine value conflicts and process through the group as appropriate. • List on a flipchart/blackboard, those considerations deemed important by participants in assessing the "appropriateness" of a patient's social environment. The following kinds of considerations might be expected by the trainer: •• Does the family/significant other offer support to the patient? (Implies more than emotional support). •• Is the family/significant other sufficiently supported to permit the continuance of support to the patient? •• What is the family's/significant other's attitude about the patient returning home? Are behaviors congruent with the stated values and beliefs? •• Does the patient appear comfortable and emotionally supported in this environment?

(Estimated Time for Activity)	(Activity)
	• Facilitate a discussion (10-20 minutes) about the diversity of familial relationships (case studies provided by the group may be highly illustrative) and how exposure to different family styles of interrelating may present value conflicts for staff in determining the "appropriateness" of a patient's social environment. Solicit from the group what conditions exist when a social environment is dysfunctional or unsuitable for the effective provision of humanistic patient care. (Assure the group, if necessary, that the topic of interpersonal relationships is one to be discussed in greater depth in a future session.)
	• Discuss with the group the environmental interventions staff can make in the establishment of a general ambiance which supports the provision of humanistic patient care. •• Physical environment - Care providers who are able to help the family "adapt" the home environment in a manner which will maximize the patient's self-sufficiency reassure the family of continued support and establish a model for the maintenance of patient independence in the environment. •• Social environment - The delivery of patient care in a professional yet sensitive manner by care providers who regard death as a normal, sad, yet not traumatic event, will reassure patient, family, and friends and may assuage some of the fears and anxieties which hamper social ease.
(30-35 Min.)	Presentation and Discussion*
	• Provide a brief conceptual introduction to the topic of "patients' rights" touching upon the following: •• What is intended by "patient rights"? •• What does the loss of these rights mean to a patient? •• What are the rights of the patient's family? •• What are the rights of the staff? •• Whose responsibility is it to assure and protect the rights of the patient?

* Portions of this training session relating to patient's rights have been adapted from the source: Training Manual For a Program of Understanding the Intent of Patient's Rights, Tacoma, The Hillhaven Foundation, 1978.

(Estimated Time for Activity)	(Activity)
	• Present brief overview of legislative activities in relation to patients' rights. •• Provide a distinction between "optional" staff responses to patients and "mandatory" responses (patients' rights). •• Note relevance of legislation for "institutional settings". Discuss monitoring mechanisms for inpatient hospice care. • Discuss those aspects of the patients' rights legislation/concept which have particular application for hospice care (inpatient and home care): •• Knowledge of condition, •• Knowledge of plan of treatment, and •• Right to refuse treatment - informed consent.
(30-35 Min.)	**Exercise** • Request a "case study" from participants (or provide own) which reflects violations of patients' rights or potential difficulties for the maintenance of patients' rights. Ask the group to "solve the problem" when special attention is paid to the following: •• Attending physicians, •• Family and friends, •• Involved public agencies, •• Other patients (if case study involves inpatient care), •• Hospice staff,and •• Hospice program (Board of Directors, Medical Director/Administrator, policies). • Process the exercise by discussing the "critical elements" of the case. (Exercise may be repeated if further exploration of issues is desirable/ necessary).
(15-25 Min.)	**Discussion** • Facilitate discussion of methodologies for ensuring professional and programmatic response to and maintenance of patients' rights in hospice care as relate to the following: •• Patients' personal possessions, •• Treatment and diagnosis, •• Interpersonal relationships, •• Patients' cultural and spiritual preferences, •• Civil rights,and •• Daily routines (whether inpatient or at home).

(Estimated Time for Activity)	(Activity)
	• Request the identification of other areas where patients' rights represent a potential issue in the care of hospice patients.
(5-10 Min.)	Closing Remarks
	• Present closing remarks about the importance of the patient care environment in influencing the attitude and general comfort of the patient.
	• Offer summarization of patients' rights discussions, identifying:
	•• Factors which mitigate against patient maintaining control and independent living, •• Desirable values for care providers which support the independent role of the dying person.
	• Facilitate the group's evaluation of the session.
	• Confirm the topic and time scheduled for the next session.

3. EXAMPLES FROM HOSPICE TRAINING EXPERIENCE: PATIENT AND FAMILY NEEDS, ENVIRONMENT AND RIGHTS

The following examples are offered as a guide to assist the trainer in the development of personal materials for training. It is not intended that any of the examples necessarily be utilized in their current form or even that their message be echoed; they offer suggested guidance only. Examples (a), (d), (e), and (f) are not verbatim transcripts of the trainer's or participants' remarks necessarily; yet dialogues closely approximate the actual dialogues from training and thus the messages are the same.

(a) Example of Trainer's Opening Remarks

Following are the brief comments made by one trainer as he introduced the topic to be covered in the three sessions on patient and family needs, environment and rights. These remarks were made at the beginning of Session 5.

> In the next couple of sessions we're going to focus on the clues which provide the basis for making more knowledgeable and sensitive decisions regarding the patients and families in your care. As the complexities of life become more apparent to patient and family with the approach of death, empathy plays a critical role as the point of departure for an awareness of needs. Our discussions of needs must focus on the patient, the family, and the patient-family as a unit.
>
> Our understanding of needs begins with an understanding of the person - the accumulation of all those life experiences which have influenced the "IS" that person has become. As was indicated earlier, understanding the "IS" within an individual is probably more difficult than performing surgery. The emphasis has been for so long on perfecting clinical skills that we've neglected the cultivation of other equally important skills. Humanistic patient care entails the continual cultivation of these non-clinical skills. Though it is the responsibility of each of you to concentrate on developing skills, it is also necessary to recognize that not one of you, or all of you as a team collectively, will understand every facet of a patient or a family, and so all needs may not be identified or understood. Each caregiver must have realistic expectations and goals about what degree of understanding can be achieved with patients or families. Carolyn B. Stevens, in addressing "The Special Needs of Long Term Patients" speaks of generic references to "patients". She suggests however, that "each (patient) is an individual with thoughts and memories known only to himself -

never to be quite totally understood by anyone else."*

So, what we strive for is that degree of comfort which can be greatly enhanced by a wholistic response to those needs which are identified. Team members aware of the positive effects on patient/family discomfort will seek information from patients and families which may provide clues as to how their needs might better be met.

(b) Examples of Written Exercises Utilized in Session 5

The following exercises are the written exercises which were utilized by a trainer in Session 5, Factors Which Influence the Understanding of Patient and Family Needs. Instructions for the use of the exercises have been previously provided in the session outline. For the trainer's convenience, each exercise is self-contained on separate pages for ease in duplication for repeated use. The exercises which appear in this example are:

- Exercise I - Values Clarification. Source: Hardin, K. and Slater, V., Experiential Exercises on Death and Dying, Salt Lake City, University of Utah College of Nursing, 1978.

  The intent of this value clarification exercise is to provide an opportunity for the care provider to explore on paper personal feelings about dying and examine his own role in caring for the dying. Sometimes the needs of a care provider and the needs of a patient may contrast, potentially creating a stressful interrelationship. An understanding and acceptance of personal needs can better prepare care providers for the eventuality of value conflict with a patient or make them more aware of when an interpretation of patient needs may in fact be a reflection of their own personal needs.

- Exercise II - The Shield. Source: Hardin, K. and Slater, V., Experiential Exercises on Death and Dying, Salt Lake City, University of Utah College of Nursing, 1978.

  This exercise is intended to make individual care providers explore issues of importance to themselves to enable them to better understand what may be of importance to the patients and families they care for. The processing of this exercise (i.e., discussions) should expose care providers to diverse

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* Stevens, C.B., Special Needs of Long Term Care Patients, Philadelphia, J.B. Lippincott Co., 1974.

responses from their peers thereby heightening their awareness of the individual nature of the dying event and the individual manner by which people express personal needs.

- Optional Exercise - I Look Forward To . . .
  Source: Hardin, K. and Slater, V., Experiential Exercises on Death and Dying, Salt Lake City, University of Utah College of Nursing, 1978.

  Time permitting, this exercise may be used as a tool to further increase care providers' understanding of the potential for loss or disruption in the dying person's life. It is an empathy-building exercise that conveys the importance of the patient maintaining some of the simple pleasures of life during the dying process. The exercise might be used as a "warm up" activity for discussion of patients' rights and the maintenance of patient independence (Session 7).

(c) Examples of Inventories of "Things to Know"

These lists of important things to know about patients and families are resultant of Exercise III conducted during a training session. The trainer explained that as these inventory items are identified the "histories" of patient, family, and patient/family as a unit begin to be revealed. Care providers are able to develop a sense for where this terminal care episode lies within the context of the family's continuity. It was noted that these inventories are a very necessary preamble to making a proper assessment of needs. These lists were developed through group process in one hospice.

List of Things it is Ideal to Know About the Patient

- Significant others
- Self concept (how they really see themselves)
- Lifestyle (may assist in understanding the patient's decisions)
- Diagnosis, treatment and prognosis
- Spiritual orientation (may affect how the patient feels about death, etc.)
- Ethnic background (different customs affect personal reactions to every day living)
- Fears and loves (deep seated feelings which may only be shown to those patient trusts)
- Education/Occupation/Avocation (important to know extent and type of education, hobbies, and how life has been spent - occupation)
- Attitudes and values (may be affected by ethnic background but not entirely)
- Financial status (amount of money or other assets affect attitudes and lifestyles)
- Activities of daily living (degree of normalcy and independence)
- Expectations (unfulfilled goals or life satisfaction)
- Comfort level (differs from person to person)
- Dietary preference (affected by ethnic background)
- Level of comprehension (dependent on ethnic background, education, etc.)
- Alternate care givers (family, friends, etc.)
- Funeral arrangements (patients are to state preferences if they wish)
- Coping mechanisms (different ways of coping with illness)
- Being controlled or controlling (may defer control to other members of family during illness)
- Knowledge of diagnosis, treatment and prognosis (opportunity to understand and share in this)
- Conflicts (with family, medical profession, etc.)
- Hopes and dreams (probably very important to terminally ill patient)

List of Things it is Ideal to Know About Family/Significant Other

- Members and significant others (controlling member)
- Knowledge of diagnosis, treatment and prognosis (ability to understand in order to help patient)
- Relationship to patient
- Place in family constellation
- Coping mechanisms (as they affect patient)
- Degree of maturity (level of support and responsibility)
- Attitudes and values
- Preferences for options on care/death/funeral arrangements (agreement with patient)
- Expectations
- Ability to provide care (financially, emotionally, physically)
- Geographical proximity
- Fears and loves (effect of patient's illness on other members of the family)
- Conflicts (increase due to illness - patient and family together)
- Education/Occupation
- Spiritual orientation
- Ethnic background
- Hopes and dreams

List of Things it is Ideal to Know About Patient - Family (as a Unit)

- Conflicts
- Relationships
- Shared knowledge of conditions
- Cultural practices
- Power and control
- Responsibility
- Place in grieving process (where each is in the grieving)
- Communication (ability to do so)
- Support system (degree of support and agreement between patient and family)
- Hopes and dreams
- Significant history of events (leading up to patient's current condition)
- Confidence in care givers and health systems (in general and in this case history)

(d) Examples of Trainer Remarks Regarding "Assessment"

The following remarks, excerpted from a trainer's comments from Session 6 on assessing patient and family needs, are not verbatim transcripts. All examples remain sufficiently accurate to convey the tone and context of the session; it was the trainer's desire to approach this difficult and sensitive topic of assessment in a manner which would be supportive and encouraging of patient care staff.

> We've previously discussed psychosocial variables which may come into play during this period of terminal illness; an awareness of variables which may impact a patient's or a family's degree of adaptation to terminal illness is the care giver's prelude to the decisions which must be made about how to retrieve the necessary information in a needs assessment. When the approach is determined, the information must then be collected, sorted through, and analysed. Many problems will become evident during a comprehensive assessment thus it becomes necessary to prioritise needs and respond to those of greatest urgency first.

* * * * *

> One of the biggest dangers in not prioritising needs is that in an effort to be responsive, staff try to resolve several problems simultaneously. Sometimes the problems staff attempt to resolve are unrelated to the more critical, presenting problem, or are problems for which the team has no problem solving skills or experience.

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> Hospice care providers frequently experience difficulty in accepting that all needs identified in an assessment may not be met. We've discussed in this group that we have problems in becoming involved in striving for perfection. Maybe it's not perfection, but if we really do accomplish some of the basic important things, then that's a wholesome step toward our goal. The real world truth is that we always prioritise and if we can do this in a thoughtful, analytical way because we're dedicated as care providers, then we will assuage some of the suffering. But we are in a world where everyone suffers loss, grief, fear of the unknown; it's our natural inclination to want to make everything painless. Grieving is human and normal and if we accumulate experiences as a team, we will become more expert at prioritising where there is greater than normal suffering. We're not going to be able to help

every single person 100%. We need to prioritize areas of need in order to make a very thoughtful evaluation of our time and resources so we will never feel we have left too much undone.

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Academically, it is necessary to discuss all the facets of what you hope to achieve with a patient and family while they are in your care. But reality dictates the necessity of identifying the high risk persons within each case or you will never accomplish as much as you would like. There are limits, and knowing where your help is most needed is essential.

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There has been some frustration associated with the whole assessment process in that sometimes patients are under your care for such a short period of time that even high priority needs are frequently not met. Here is where knowledge of hospice as a resource must extend to the community. The staff of one hospice I was associated with were very troubled the first year of operation because patients were referred to them such a short time before death that very little could be accomplished. Following death, a brief resumé was sent to the referring physician which stated what was done for the patient in addition to what staff felt could have been accomplished had more time with the patient been available. When the general medical community better understands the comprehensive nature of hospice care, responding to a diversity of needs identified through a comprehensive assessment, referrals will be more appropriately timed and you will have time to accomplish some of the things you couldn't when patients arrived so late.

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Given the realities of limited time and pressing priorities, often care givers don't take full opportunity to elicit information from patients or families while providing care. The information does not have to be obtained through one-on-one interviews across a desk; assessment is on-going throughout the course of care and information can be obtained by the sensitive care giver through casual conversation. Also, it's very important to share with one another so that we have an opportunity to become more aware through the experiences of others on the team.

(e) Example of Trainer's Remarks Relevant to Patients' Rights

The following comments were made by a trainer to introduce the topic of "patients' rights". The transcript is not a literal translation of the dialogue from Session 7, however, the reader should be able to discern the general tone established in the session.

> To continue, I know the day wouldn't be complete without a handout.* I caution you that this Xerox material refers to Medicare. The reason I brought this is because there are a couple of pages upon which the actual law for the patients' rights regulation is predicated. This is the major document which is used for interpretation; surveyors use it to determine how the regulation is implemented. This is a remarkable thing because it is the first time in our history we have legislated anything about patients' rights. You hear a great deal about this on national levels but this particular area of patients' rights is the least enforced, least understood and people find it hard to determine how it should be enforced. Many of us in the field fully expect a much greater emphasis in the foreseeable future on the monitoring of patients' rights. For now however, you in the home health care service are on the brink of having to deal with these same issues so you should be aware of it. Once rights are legislated you have a legal obligation to observe them, but what's more important, you have to have some kind of understanding as a team as to what are the critical rights and keep sensitized to those rights so we don't inadvertently transgress them. This is not usually done deliberately but we fall victim to an age-old system or sometimes we transgress without really knowing we are. We're currently having a lot of trouble with semantics. Some rights have been legislated. But often when we are discussing issues where rights might be concerned, we're really saying that patients should be given a preference for an action or a decision. This is not the same as the legislated rights where there is no option - only rights.

(f) Examples of Group Comments Relating to the Issue of "Informed Consent"

In Session 7 a discussion of "patients rights" explored the patient's right of access to the best available medical information in order to enable a knowledgeable decision. Session participants, based on personal experience, made some observations about the issue of informed consent. (Remarks are not verbatim).

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* Trainer's Referenced Handout: Subpart E, Patient's Rights, Federal Register, Volume 45, No. 136, July 14, 1980 - Proposed Rules.

I have a very long-time friend in Sarasota that has terminal cancer. Recently while hospitalized for about two weeks she shared her semi-private room with three different patients. Each was totally bald from chemotherapy. Then they came in and asked her if she wanted chemotherapy. It didn't even occur to me at the moment, but it occurred to me later, that she had been so preconditioned by her three roommates, how could you say she had a neutral arena in which to make an informed decision?

* * * * *

More often than not patients won't say they refuse to follow our instructions - they are passively adamant. They refuse to take the medicine - they don't understand chronic pain control. They are still operating on the acute pain regime. If their prescription reads, "take one every four hours", and we have gotten an order from the doctor for them to take more, it comes down to a matter of trust. I don't know how we can convey that information so that they will accept it. I know for some of them they feel they are being addicted. They can't understand the difference in taking it for comfort and taking it for need. Sometimes it becomes very difficult - you can't say "you'll die before you are addicted".

(g) Example of a Handout for Discussion of Patients' Rights

The following "Bill of Rights" was created at a workshop entitled, "The Terminally Ill Patient and the Helping Person", sponsored by the Southwestern Michigan Inservice Education Council. A handout of this nature would be utilized in Session 7 and would provide a starting point for a discussion of the rights of the dying.

The Dying Patient's Bill of Rights*

I have the right to be treated as a living human being until I die.

I have the right to maintain a sense of hopefulness however changing its focus may be.

I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right to participate in decisions concerning my care.

I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.

I have the right not to die alone.

I have the right to be free from pain.

I have the right to have my questions answered honestly.

I have the right not to be deceived.

I have the right to have help from and for my family in accepting my death.

I have the right to die in peace and dignity.

I have the right to retain my individuality and not be judged for my decisions which may be contrary to beliefs of others.

I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.

I have the right to expect that the sanctity of the human body will be respected after death.

I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

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*Source: American Journal of Nursing, 75, January 1975, p. 99.

4. SELECTED RESOURCE MATERIAL FOR TRAINING: PATIENT AND FAMILY NEEDS, ENVIRONMENT AND RIGHTS

The following selected written resources represent a collection of highly relevant works which will provide additional information to trainers and training participants about the topics explored in this portion of the training. Whenever possible the citations listed reflect writings from a cancer related or hospice specific perspective. For the convenience of the user the references appear under two headings:

- Assessing Patient and Family Needs
- Patient Care Environment and Patients' Rights

These headings have been selected based on the interrelatedness of the referenced material found under each. Many references found to be helpful in understanding the needs of patients and families were the same references found to deal with actual assessment procedures. Similarly, the topics of patient care environment and patients' rights are so closely related that there are common references for both of these topics. All citations appear in alphabetical order under the relevant heading.

Assessing Patient and Family Needs

Bahnson, C., "Psychologic and Emotional Issues in Cancer: The Psychotherapeutic Care of the Cancer Patient", Seminars in Oncology, 2:4, December 1975, pp. 293-309.

Bloom, J. et al, "Problem-Oriented Charting", American Journal of Nursing, 71:11, November 1971, pp. 2144-2148.

Feder, S., "Psychological Considerations in the Care of Patients With Cancer", Annals of the New York Academy of Sciences, 125, pp. 1020-1027.

Kaplan, D., Grobstein, R. and Smith, A., "Predicting the Impact of Severe Illness in Families", Health and Social Work, 1:3, August, 1976, pp. 72-82.

Koff, B., "Control of Symptoms", in Koff, T., Hospice A Caring Community, Cambridge, Winthrop Publishers, 1980, pp. 42-65.

Kulik, H., "Pain Assessment", Norwalk, CA, Kaiser Foundation, January 1979.

McKorkle, R. and Young, K., "Development of a Symptom Distress Scale", Cancer Nursing, October 1978.

Parkes, C., "Evaluation of Family Care in Terminal Illness", in Pritchard, E. et al (eds.), The Family and Death, New York, Columbia University Press, 1977.

Payne, E. and Krant, M., "The Psychosocial Aspects of Advanced Cancer: Teaching Simple Interviewing Techniques and Record

Keeping", Journal of the American Medical Association, 210:7, November 17, 1969, pp. 1238-1242.

Saunders, C., "Patient Care: An Introduction", in Vere, D. (ed.), Topics in Therapeutics, London, Pitman Medical Publishing Co., 1978.

Schell, P. and Campbell, A., "POMR-Not Just Another Way to Chart", Nursing Outlook, 20:8, August 1972, pp. 510-514.

Twycross, R., "The Measurement of Pain in Terminal Cancer", Journal of International Medical Research, 4, April 1976, pp. 58-67.

Woody, M. and Mallison, M., "The Problem-Oriented System", American Journal of Nursing, 73:7, July 1973, pp. 1168-1175.

Yarnell, S. and Atwood, J., "Problem-Oriented Practice for Nurses and Physicians", Nursing Clinics of North America, 9:2, June 1974, pp. 215-228.

Patient Care Environment and Patients' Rights

Alsofrom, J., "Hospice Way of Dying at Home With Friends and Family", American Medical News, 8, February 21, 1977, pp. 7-9.

Annas, J., "Rights of the Terminally Ill Patient", Journal of Nursing Administration, March-April 1974, p. 40.

Armstrong, M., "Dying and Death - and Life Experiences of Loss and Gain: A Proposed Theory", Nursing Forum, 14:1, 1975, pp. 95-104.

Bernhard, R., "The Dehumanized Hospital Hurts You - And Your Patients", Nursing Digest, Spring 1977.

Chan, L., "Hospice: A New Building Type to Comfort the Dying", American Institute of Architects Journal, December 1976, pp. 42-45.

Cotter, Z., "Institutional Care of the Terminally Ill", Hospital Progress, 52, June 1971, pp. 43-48.

Gargaro, W., "Informed Consent: Part II, How Much to Tell the Patient", Cancer Nursing, 1:2, April 1978, pp. 167-168.

Gargaro, W., "Informed Consent: Part III, The Nurse's Right to Inform", Cancer Nursing, 1:3, June 1978, pp. 249-250.

Hillhaven Foundation, Training Manual for a Program of Understanding the Intent of Patients' Rights, Tacoma, WA, The Hillhaven Foundation, 1978.

Koff, T., "The Hospice Environment", in Hospice A Caring Community, Cambridge, Winthrop Publishers, 1980, pp. 123-134.

Kron, J., "Designing A Better Place to Die", New York, 9:43, 1976, p. 39.

Margolis, J., "Conceptual Aspects of A Patients' Bill of Rights", Connecticut Medical, Vol. 39, September 1975, pp. 582-587.

Modlin, H., "Balancing Patients' Rights With the Rights of Others", Hospital Community Psychiatry, Vol. 25, July 1974, pp. 474-475.

Paulen, A., "Living With Cancer: The Rights of the Patient and the Rights of the Nurse", in Peterson, B. and Kellogg, C. (eds.), Current Practices in Oncologic Nursing , Vol. I, St. Louis, C.V. Mosby Co., 1976.

Pellegrino (ed.), "Protections of Patients' Rights and the Doctor-Patient Relationship", Preventive Medicine, 4:4, December 1975, p. 398.

Ramsden, E., "Patients' Right to Know, Implications for Interpersonal Communications Process", Physical Therapy, 55:2, February 1975, pp. 133-138.

D. COMMUNICATION SKILLS AND STYLES: PATIENT/STAFF RELATIONSHIPS, STAFF/STAFF RELATIONSHIPS AND OTHER HEALTH PROFESSIONALS/STAFF RELATIONSHIPS

An instrumental component of the humanistic patient care philosophy is, of course, the patient care provider. As such, it is incumbent upon the patient care provider to continually cultivate those skills required to expouse the humanistic philosophy. An examination of the skills necessary to develop and enhance the person-to-person relationships so critical to the success of humanistic patient care goals, is the intent of this section. Issue identification and actual communication skills training with relation to interpersonal relationships are addressed in the following training categories: Session 8, Communication Issues and Skill Building; Session 9, Patient/Staff Relationships; and, Session 10, Interpersonal Skill Building as a member of the Hospice Team. Background information, examples from hospice training experience and a bibliography of relevant resource materials are also included within this section to assist in the preparation of the trainer(s).

1. BACKGROUND INFORMATION FOR TRAINERS

(a) Timing of Sessions

With the conduct of these final sessions in the "formal" training, we have come full circle in our trio of identified categories of training - personal development, knowledge and understanding, and skills. Initial sessions focused upon the personal development of hospice staff through an exploration of personal values and views about humanistic patient care; opportunities to increase knowledge and understanding were afforded through didactic and affective learning processes which explored the many diverse variables and environmental conditions influencing the interrelationships between patients, families, and staff. Building upon these integral foundation pieces, the focus now becomes skills. The learning of interpersonal relationship-building skills is warranted given our previous concerns for increasing participants' awareness of values and their relatedness to behavior; examining substantive and intuitive information about psychosocial issues in caring for patients and families; and exploring the implications of diverse value systems interacting with the varied psychosocial issues.

Throughout these materials, the emphasis of training in humanistic patient care has been based upon the affirmation of life. It has been illustrated that dying, as one segment of the life cycle, must continue to affirm the

quality and dignity of life, even in the presence of advancing disease. As management of both the clinical and the psychosocial aspects of dying become the concern, the stress inherent in these goals is often reflected by strained or dysfunctional interrelationships among those involved in the attainment of the goals. So it is at this time that the attention is turned to an examination of the distancing and miscommunication which often occurs between hospice staff and the patients/families which they care for, the team member they work with, and the health/social service colleagues they rely upon within their mutual community. An unwillingness, or inability - due to lack of skills, to express feelings, results in a greater suppression of emotions throughout the network. Without awareness of personal feelings in professional interactions there may be the inability to understand the feelings and responses of patients.

(b) Session Relatedness to Process Issues

"Awareness" issues have permeated the content of these training materials; around the discussion of values (intrapersonal awareness) a major goal has been the ability of staff to be "non judgmental" while maintaining personal integrity. The focus has now evolved in a very pronounced fashion to the issue of interpersonal awareness. Though only addressed as a reflection of how we interact and communicate with others, intrapersonal issues remain a significant theme in a discussion of interpersonal relationship building skills. The materials principally depart from cognitive learning modes to affective and experiential learning modes. With this departure comes a hard focus upon the process issues which reflect the more concrete skills areas of listening, communication, and stress management. The emphasis is not "how do you feel about?" but rather, "how do you deal with someone who feels . . . ?" Management/Supervision issues are implied by virtue of participants' heightened awareness and associated increased skill capabilities which presumably will influence the manner in which management and supervision practices will be conducted. (The management/supervision issue is ancillary to the primary foci of this session and is dealt with in a more direct fashion in Session 11). The material presented in this section, coupled with the experiential activities which provide an opportunity for interaction between participants, reveals much about the specific communication skills and approaches employed by participating hospice staff. This knowledge equips each individual with the valuable awareness necessary to begin to improve upon existing relationships with co-workers, including better support of those persons. Each participant's increased self-awareness of personal interrelationship skills and styles is another critical factor in improving the quality of patient/staff relationships.

(c) Number and Sequence of Sessions

Issues addressed and their corresponding presentations, discussions and exercises have been presented in this

sequence of three separate sessions for a number of reasons. *Session 8 appears first in the sequence because it begins* with a topic which could be regarded as least "threatening" - communication issues and skill building. Both small and large group activities are employed permitting participants to become comfortable with the learning format and their own abilities. Session 9 focuses upon patient/staff relationships which, in the training experience, served to identify through group activity, several key stress issues inherent in these relationships. The "safe" environment, by then firmly established, enabled processing which would support some participants expressing stressful feelings. The session drew upon many of the communication skills practiced in the previous session.

Though the materials have been developed to reflect three sessions of three hours in duration each, it is conceivable that Sessions 8 and 9 could be combined. In the event hospice staff to be trained have received previous training in communication skills and/or demonstrate sophisticated use of communication skills, a joint session would omit the basic skill building exercises conducted in Session 8, while emphasizing the use of those skills in an examination of issues identified in Session 9. Should this approach be undertaken, it is suggested that the length of the combined session be expanded to four hours minimally.

Session 10, the concluding session in this sequence, explores principally the interpersonal relationships among staff. A greater degree of skill sophistication is required, and certainly the assurance of a safe environment must be present for meaningful discussions and activities to take place with maximum involvement from participants. Supportive activity and trainer processing is built into this session outline as it is intended to be the concluding communication session and participants would optimally depart the session without any significant unresolved issues.

(d) Trainer Planning of Sessions

This series of sessions represents the most experiential portion of the training in humanistic patient care by virtue of the interpersonal skill building activities suggested. The topic of "interpersonal relationships" is one which may be met with some resistance for fear of "rocking the boat". Though presumably all participants will be interested in improving the quality of their relationships with patients/families, staff, and colleagues within the community, it may be feared that the means to this end would present them with some conflict and discomfort. The trainer must have an appreciation for the highly sensitive environment which hospice is, an awareness of the mission which guides the participants, and an understanding of the organizational leadership which establishes the philosophical tone and

entertains certain expectations of staff. A preparedness to meet with some resistance natural to all groups, and a corresponding demonstration of the sensitivity required to put participants at functionable ease, are trainer characteristics which will most likely be necessary.

Session "working outlines" have been provided to assist the trainer in the identification of interpersonal and communication issues of particular relevance to hospice staffs. However, it is recognised that training methods and activities concerned with teaching interpersonal relationship building skills, and the more general communication skills, are diverse and numerous. Each trainer has the obvious option to utilize those approaches and activities which most closely reflect personal biases about the teaching of skills but training issues should be considered when selecting alternate approaches. For those who will use the exercises/activities provided in these materials, it should be remembered that "small group" denotes a group size small enough to enable each member to become actively involved in the exercise. Utilization of informational handouts or assignments for reading outside the session, will discourage "note taking" by participants while encouraging their greater participation. Ample instruction has been provided for all activities/exercises and numerous sample handouts, homework assignments, and audio/visual suggestions have been offered. In the case of handouts, the trainer must, of course, duplicate all those contained within these materials and any others they have identified prior to the session where they will be utilized. Some charts developed by trainers during the training sessions may be regarded as useful handouts; these would also require preparation and duplication. Each session outline offers similar abbreviated suggestions for preparation of sessions.

For Sessions 8, 9, and 10, the room where training will occur takes on new importance, since several exercises require the larger group to break into dads and triads for small group activity. The room should be of sufficient size to comfortably accommodate however many small groups there may be; with distance enough between each to permit the activity to be conducted with minimal distraction. Accommodations should convey a feeling of "community confidence" necessary to conduct confidential sessions. If previous humanistic patient care training sessions have been interrupted, it would behoove the trainer to seek assurances that interruptions will not be made unless absolutely necessary; any refreshments to be served may be made available at the onset of the session to preclude those interruptions.

(e) Trainer Behavior in Sessions

The highly experiential nature of these three sessions (8, 9, 10) makes a strong case for a supportive trainer possessing many skills in communication or interpersonal relationship-building who is capable of conducting a task-oriented meeting. It is quite conceivable that sessions which are not carefully orchestrated by the trainer may become group therapy sessions with a great deal of time spent on supporting group members and far too little emphasis on actually learning and practicing skills; this is not intended. Rather, the trainer must establish a supportive leadership posture which while remaining "on task", is responsive to shifts in the group when it is felt that an emerging issue has relevance for group movement in a broad interpretation of "skill development". For the most part, the trainer will find that the built in exercises tend to guide the sessions naturally. Trainer skills in supporting, active listening, clarifying, probing, reflecting feelings and behavior, and even confrontation are behaviors which will potentially be demonstrated in the various role play situations included in the sessions. Whether through one-on-one feedback mechanisms or through a trainer-suggested "hypothetical" exchange, a non threatening practice of heightening participants' awareness of personal communication skills and styles must be employed. In Session 8 this self-awareness is necessary in order to finalize the following sessions' agendas (i.e., the identification of the skills to be focused on in training). Small group activities, found in this session and elsewhere, leave to the discretion of the trainer the actual ground rules for practicing skills. Some hospice administrators, or participants themselves, may express a desire to not deal with personal lives in role plays demonstrating interpersonal relationship skills (particularly conflict); the trainer, however, may detect that "team" role plays would be potentially harmful to the group's sense of "safety". Each trainer must be aware of the limitations particular to each group and setting.

One purpose of Session 9, patient/staff relationships, is to explore stress management issues. This topic by nature lends itself to a "support session" format; but "support" is intended to be conveyed through the development of skills or on-going strategies which may be employed by participants rather than received from the trainer. Didactic presentations offer the participants some insight which will assist them in the further development of personal techniques but the trainer is encouraged to introduce new modalities (e.g. relaxation exercises).

Session 10 focuses heavily upon the feeling, "anger", and the communication skill, "confrontation". The trainer must be able to convey to participants the positive aspects

of these and provide opportunities for participants "to view" personal anger and to acquire skills which will make confrontation more successful and "satisfying". Processing of all exercises and discussions is particularly critical in this session as it is the last session on communication and possibly the last of the formal training sessions in humanistic patient care. The trainer must offer a great deal of encouragement to participants to support them in the continual practicing of skills.

2. OUTLINE OF TRAINING: COMMUNICATION SKILLS & STYLES; PATIENT/STAFF RELATIONSHIPS; STAFF/STAFF RELATIONSHIPS; AND OTHER HEALTH PROFESSIONALS/STAFF RELATIONSHIPS

Included in this section are three model outlines exploring the communication skills and modes inherent in the development of positive, meaningful human relationships. The first session outline explores participants' own communication skills and styles; the second outline examines interpersonal styles of communicating, principally that relationship between staff and patients; and, the third outline deals with those communication issues which are more prevalent in staffs' relationships with other staff members or with health professionals outside the hospice setting with whom they must periodically interface. The skills examined, while not all inclusive, are those which foster the provision of humanistic patient care by virtue of improving any one of the relationships which represent a piece of the hospice support network. Session outlines are intended to be used as models and as such, suggested content or strategy may be modified to better accommodate the needs of the hospice group and/or the specific skills of the trainer.

Session I: Communication Issues and Skill Building

Purposes of the Session

- To create an awareness of personal communication skills and styles,
- To identify issues for inter- and inter-personal skill building which enable the provision of humanistic patient care, and
- To explore communication skills beneficial in the establishment of humanistic relationships.

Participant Preparation

- None

Trainer Preparation

- Review sections of the series: Monograph 2, Chapters I, II, IV; Monograph 3, Chapters II, and IV; Monograph 6, Chapter V.

- Review, if desired, the following recommended major resources:

  - Communication Research Associates, Communicate! A Workbook for Interpersonal Communication, second edition, San Diego, Learning Resources Corpora-

tion, 1980. (Trainer-led exercises for the group).

- Hollister, W. and Shearon, J., "Teaching Relationship Building Skills", American Journal of Public Health, January 1976.
- Jones, J. and Bohr, L., "The Jones-Bohr Listening Test", La Jolla, University Associates, 1976. (Tape/album and written instrumentation for trainer administration).
- Lesegne, L., "Physician's Behavior Toward the Dying Patient", in Brim et al (eds.), The Dying Patient, New York, Russell Sage Foundation, 1965.
- Luft, J., "The Johari Window: A Graphic Model of Awareness in Interpersonal Relations", in Porter, L. and Mill, C. (eds.), Reading Book for Human Relations Training, Arlington, VA, NTL Institute, 1976 edition, pp. 13-14.
- Milano, J. and Portnoy, E., Communicating Empathy, La Jolla, University Associates, 1980. (Tapes and exercises for the trainer).
- Tournoux, R., Communication with the Family III, New York, Thomas Publishing, 1968.

- Collect/Prepare and reproduce any handouts for discussion (see "Examples from Hospice Training Experience").

Estimated Time for Activity	Activity
	Opening Remarks
15-10 min.)	• Introduce the day's training topic and provide a brief rationale for developing a greater awareness of participants' own communication skills and styles and the implications that these have for successful communication of humanism in patient care. • Review the experiential and voluntary nature of the session; encourage participants to become involved in exercises to the degree comfortable emphasizing task-oriented purpose of session.

(Estimated Time for Activity)	(Activity)
	• Describe own role as a facilitator of personal awareness and skill development in communications (see Examples from Imagine training experience).
	• Solicit comments and questions from the group and respond to these.
(10-15 min.)	Exercise
	• Inform the group that the purpose of the opening exercise is to generate a list of communication issues - relating to patients, families, staff, or other health professionals - about which they would like to talk (see Examples from Imagine training Experience).
	• Divide the larger group into ten or more groups of a "workable" size to brainstorm communication issues to be discussed; participants are to create "how to" statements (e.g. how to deal with value conflicts between self and patient when interacting).
	• Observe small group activity (10-15 minutes); clarify exercise instructions if necessary. (Note: It may be helpful if an individual recounts to his/her smaller group an unsatisfactory or negative exchange or circumstance between self and another. The small group will assist in the creation of a "how to" statement to accurately reflect the assistance desired in the resolution of the conflict.)
	• Position self at blackboard/flipchart in view of all groups; create topic headings for four lists:
	- Self "how to's" - must know "self" before it can be communicated to others; self is continually evolving and internal conflicts emerge which must be resolved or coped with.
	- Other "how to's" - differing expectations and perceptions create barriers to communication between individuals which frequently must be resolved to further development of the relationship.
	- Relationship (needs) "how to's" - everyone has needs that are fulfilled or unfulfilled; frequently persons are unaware of the needs of others or how to meet those needs. Communication facilitates the exploration of unmet needs.

(Estimated Time for Activity)	(Activity)
	●● Relationship (values) "how to's" - values represent basic beliefs which may be challenged by attitudes, values, or behaviors of others. Communication aids in the recognition and/or acceptance of differences.
	• Request volunteer to begin creation of the "how to" lists; clarify "how to" statements; discuss with group the appropriate placement of the statements and record under selected category.
	• Interact with participants during the development of the lists, providing support, making appropriate self disclosures to contribute to feelings of openness, etc.
	• Commit to establishing a format in the next few sessions which will facilitate working through some of the defined issues. Clarify to the group that resolution of all issues may not be achieved, but possibly closure will be possible (i.e., discharge of all the emotional stress contained in the issue; if it relates to "relationships" this implies that the other individual(s) involved in the interaction have been approached and similarly relieved of the stress. The relationship remains intact and communication is open).
(20-30 Min.)	Presentation and Discussion
	• Present briefly (5-10 minutes) and discuss some thoughts on unrealistic expectations for interpersonal communication (theoretical works of Virginia Satir*):
	●● Can't ask someone to feel like we feel; feelings can't be forced. Also can't take feelings away from others; guilt or whatever the feeling can only be resolved within selves.
	●● Can't ask someone to think the way we think; persuasion may be attempted but without any guarantees for success.
	●● Can't demand someone to do something; may be successful in getting others to conform to a certain pattern but the option is theirs to change at any time.

* Satir, V., Peoplemaking Palo Alto, Science & Behavior Books, 1972.

(Estimate Time for Activity)

(Activity)

Demands usually backfire because people must be motivated to want to do something.

- Examine with participants the interpersonal components which contribute to good communication:
  - Self concept - people's beliefs about themselves are critical factors in determining communicative behavior; most important variable in successful communication.
  - Listening - an effective listener has ceased with confronting and has begun to listen (shifting from a "sending" to a "receiving" position); listens to the meaning behind the words.
  - Clarity of expression - each individual must have a clear picture in his/her mind about what he/she feels and is trying to express. (Often individuals are unaware of what it is they want or need.)
  - Coping with anger - anger in others can't be dealt with until each of us has knowledge of what our own anger is like. Angry feelings must be expressed constructively not destructively.
  - Self-disclosure - an individual can't really communicate with another or get to know that person unless some self-disclosures can be made. "Self-revelation is a symptom of a healthy personality".

- Explore "ownership" of various problems in communication based on the above.

- Disseminate the handout on "Communication in Small Group Learning" (see Examples from Hospice Training Experience); request that the group read the handout prior to the next session.

(25-35 Min.)

Role Play Activity

- Request a volunteer from the group willing to share a recent experience which resulted in a substantial amount of personal stress. The interaction or circumstances may have involved a patient, family, staff person, or other health professional outside of hospice.

- Request participants to be aware of metacommunications during the role play activity:
  - Attention to facial expressions and body movement/posture, and
  - Congruence between stated feelings and demonstrated behavior, voice tones, etc.

(Estimated Time for Activity)	(Activity)

- Model behavior for the group by communicating with the volunteer demonstrating clarifying questions, active listening skills, etc.

- Ask the group what they observed in the role play activity; process accordingly.

(25-35 Min.)

Small Group Skill Building Exercise

- Instruct participants to break into groups of three.

  - Two people role play a work-related or personal life situation (one which an individual would like to confront but is reluctant to).
  - Individual reluctant to confront issue begins exercise with one other in the triad.
  - Third person acts as observer; listening for permissable communicative levels - silence, non-committal, door openers, content paraphrase, and active listener.
  - Observer records what modes were used other than allowable choices.

  (Note: Participants may refer to "Listening Skills", pages 4-5 of the handout, for additional assistance in this exercise.)

- Permit time (15-20 minutes) for small group activity; reconvene the larger group and process the exercise.

(5-10 Min.)

Closing Remarks

- Instruct participants to write down three feelings that each is aware of within themselves; at the present moment; circle the one which is most pronounced. Proceed around the room asking for the circled feeling from each; respond as necessary. (If participant response to this brief exercise is not evaluative in nature of the day's session, solicit more direct feedback from the group.)

- Disseminate second handout as homework (see example "d" in Examples From Hospice Training Experience). Remind group to read first handout (example "c") before next session.

- Adjourn session with expressed appreciation for openness and contribution.

Session 9 Patient/Staff Relationships

Purposes of the Session

- To discuss awareness issues in the patient/staff relationship and the resultant implications for enhancing the humanism in patient care through communication,
- To explore intrapersonal styles of communicating when relationship building with patients/families, and
- To identify stress management issues and explore strategies for the continued support of the care provider through improved communication skills.

Participant Preparation

- Review the 7-page handout disseminated in the previous session.
- Complete the exercise assigned in the previous session.

Trainer Preparation

- Review sections of the series: Monograph 2, Chapters I, II, IV; Monograph 3, Chapters II, VI; Monograph 4, Chapters IV, V.
- Review, if desired, the following major written resources:
  - Bahnson, C., "Psychologic and Emotional Issues in Cancer: The Psychotherapeutic Care of the Cancer Patient", Seminars in Oncology, 2:4, December 1975, pp. 293-309.
  - Beszterczey, A., "Staff Stress in Newly-Developed Palliative Care Service: The Psychiatrist's Role", Canadian Psychiatric Association Journal, 22:7, November 1977, pp. 347-353.
  - Harker, B., "Cancer and Communication Problems: A Personal Experience", Psychiatry in Medicine, 3, 1972, pp. 163-171.
  - Hollister, W. and Edgarton, J., "Teaching Relationship-Building Skills", American Journal of Public Health, January 1974.
  - Milnes, J. and Bertcher, H., Communicating Empathy, La Jolla, University Associates, 1980. (Exercises and tape

included).

- Pattison, E., "The Living-Dying Process", in Garfield, C. (ed.), Psychosocial Care of the Dying Patient, New York, McGraw-Hill, 1978, pp. 133-168.
- Pfeiffer, J. and Jones, J., A Handbook of Structured Experiences for Human Relations Training, Vols. I-VII, Iowa City, University Associates Press, 1978.
- Satir, V., Peoplemaking, Palo Alto, Science and Behavior Books, 1972.

(Estimated Time for Activity)	(Activity)
(5-10 Min.)	Opening Remarks

- Review the purpose and agenda of the day's session and obtain group agreement (see Examples from Hospice Training Experience).

- Provide brief rationale for greater understanding of the implications of positive patient/staff relationships:

  - Achieving patient compliance,
  - Managing patient care,
  - Supporting the patient emotionally,
  - Preparing patient/family for death, and
  - Managing own stress.

- Provide an opportunity for participants to briefly raise questions about the previous session before beginning; respond to questions and comments.

- Restate the voluntary nature of participation in session discussions; encourage participants to become involved to the degree comfortable emphasizing the task-oriented nature of training sessions.

(Estimated Time for Activity)	(Activity)
(10-20 Min.)	Opening Exercise

- Request participants to ease into the day's activities by sharing with the others the time of day each "feels most alive" during the working day (e.g. when communication between patient and self is going smoothly, when assisting in the resolution of a staff person's stress).
- Model active listening skills as each participant responds in turn to the question.
- Offer rationale for exercise and encourage brief discussion:
  - Useful means of determining where everyone is coming from.
  - Opportunity for participants to reflect on favorable aspects of their jobs.
  - Insightful information offered to other care providers, and
  - Listening skills demonstrated.

(15-25 Min.) Presentation and Discussion - Patient Fears and Staff Response

- Present briefly some of the various fears which dying persons may face; facilitate a discussion of interventions to be considered and specific ways care givers may assist patients in coping with these fears.*
  - Fear of the unknown - the uncertainty of what lies ahead as the disease manifests itself and death approaches. A relationship of confidence and trust will enable the patient to ask questions and

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* Presentation and discussion issues principally adapted from: Pattison, E., "The Living-Dying Process", in Garfield, C., (ed.), Psychosocial Care of the Dying Patient, New York, McGraw-Hill, 1978, pp. 133-168.

(Estimated Time for Activity)	(Activity)
	receive reliable answers. Provide specific answers when possible; indicate which questions will only be answered over time. Assist the patient in distinguishing between questions which deal with reality issues of life (for which there are real responses) and philosophical, religious or speculative questions (for which only opinions and beliefs can be offered).
	•• Fear of loneliness - the sense of isolation from self and others which may be accompanied by a mutual process of withdrawal. Engaging the patient's interest in everyday relations and tasks, if desired, may allay some of this fear. Assurance of the continuing interest and availability of people also reassures.
	•• Fear of sorrow - the overwhelming sense of emotional pain is precluded by avoiding situations which may stir feelings of sorrow and grief. Establishing an atmosphere which conveys the acceptance of grief as an appropriate emotion facilitates the sharing of sorrow between patient and family and permits more opportunity for working through emotions.
	•• Fear of loss of family and friends - the seperation between self and loved ones; a real loss which requires mourning. Interpersonal relationships, under close scrutiny of the patient, may create a variety of ambiguous and conflicting emotions. Assist the patient and family in accepting the array of emotions, even feelings such as hate and anger which may formerly have had negative connotations for the patient.
	•• Fear of loss of body - the loss of an integral part of self concept; external disfigurement

(Estimated Time for Activity)	(Activity)
	from advancing disease or previous treatments may be more tolerable than the unknown distortions occurring internally. Keep the patient accurately informed of actual and anticipated bodily processes. Reassure all that loss of bodily functions is not shameful and assist patient only to the extent that he is not personally able (or train family member to do so if this is more acceptable to patient).
••	Fear of loss of self control - the slow down or malfunctioning of the physical organism; loss of control over mind threatens personal integrity. Assist in making distinctions between various "control" issues: control of life events; control of self; and control of body. Encourage and support continued control of life events regarding specific decisions patients are still able to make (e.g. wills, family concerns, funeral, burial). Support the direction and manner in which the patient has chosen to live until death. Provide continuous opportunities for the patient to exercise physical management of own body to the extent possible.
••	Fear of suffering and pain - the socio-cultural anticipation of, and response to, pain. Respond with heightened involvement, medical information sharing, and assurances that the patient will be involved in management of own personal pain. Advise family of the multiple dimensions of pain and suffering.
••	Fear of regression - the instinctive regression into remoteness as death approaches and the inherent fears of this internal state. Continued encouragement for active engagement long after the patient has lost the will communicates a message of unacceptability. Assist

(Estimated Time for Activity)	(Activity)
	family in communicating shameless, guiltless, fearless response to regression.
	• Discuss the implications that these fears have for varied interventions with patients and families. (Staff may be encouraged to cite case studies which provide models of positive interventions or provide examples when a particular intervention failed. In the latter case the trainer should offer support and facilitate a discussion of options which may have been employed.)
	• Encourage participants not to be afraid of attempting new approaches in offering support or managing dysfunctional conflict when working with patients/families.
	• Offer some principles for the care giver when an intervention is warranted; discuss associated communicative processes which reaffirm a supportive, non-judgmental relationship between patient and staff.*
	○○ Determine actual stressor(s) and presenting problem(s) for the patient; respond to the emotions generated by these relevant issues.
	○○ Separate out issues as they arise to avoid the patient becoming overwhelmed and confused by the possibly multiple conflicting issues; support the confrontation and possible resolution of each issue one at a time according to patient need.
	○○ Respond to the patient's actual dying experience without the imposition of personal values which require conformity to personal/idealized concepts of dying.
	○○ Recognize and respond to both the accepting and denying processes within the patient, family, and self.

* Pattison, E., "The Living-Dying Process", in Garfield, C. (ed.) Psychosocial Care of the Dying Patient. New York, McGraw-Hill, 1978, pp. 133-148.

(Estimated Time for Activity)	(Activity)
(35-45 Min.)	Presentation and Discussion - Awareness Issues

- Review briefly (5-10 minutes) the issues of awareness necessary for a successful interrelationship.*

  - Awareness of self - the ability to make person-to-person contact begins with intrapersonal awareness. Each person has major parts that create the total person; each person is consciously aware of some of these parts and other parts are outside of one's own awareness. The more parts known intrapersonally, the greater one's ability to make person-to-person connections with diverse types of people. Self-awareness increases one's resources necessary for survival; the health provider role is demanding and absorbing and sometimes individuals lose sight of their humanness - with all its faults and limitations. Individuals may feel that they have assumed the responsibility to be something "more" than mere persons. This burden of responsibility interferes with the ability to establish effective person-to-person relationships with patients.
  - Awareness of others - an awareness of others and their 'inner states' is a prelude to a person-to-person relationship. Non-verbal behavior usually offers sound clues about inner feelings (i.e. facial expressions, posture, eye movements). Patients always have a number of different feelings about the state of their illness and associated issues which are brought to the attention of the care provider either subtly or overtly. Staffs' ability to discern and respond to these feelings (perhaps merely by

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* Presentation and discussion issues principally abstracted from: Bahr, V., Programming. Palo Alto, Science and Behavior Books, 1973.

Estimated Time for Activity	Activity
	acknowledgement is very helpful in establishing a positive relationship with a patient. There is a link between one's ability to accept self and also be accepting of others. Often those characteristics that are not tolerated in others are the same characteristics not tolerated within one's self. Obtaining knowledgeable about another's values and life experiences can be rewarding but also disquieting; increased awareness and knowledge invites the possibility of having to reexamine one's own values and relinquish personal life experiences.
	● Awareness of context - an awareness of the context in which individuals relate to one another is influential in the establishment of person-to-person encounters. Though such relationships may occur in any setting, quiet and privacy are usually more conducive to meeting feelings. Environment or persons within the environment can help or hinder the relationship sought.
	● Various examples of dysfunctional communication styles when one of the three aspects of interpersonal relationships is not recognized or is underused. (When individuals are stressed or perceive self-esteem to be threatened, they run the risk that one or more aspects will not be represented in the exchange.)
	● Missing tokenness of "other") - When some important aspect of one's psychological survival is at the risk, one may overlook the importance of establishing an effective person-to-person communication with another, and concentrate only on self and meeting personal needs. Under these circumstances, the risk is high that one will be highly critical of the other and blame that person for what's not going right in one's own life.

Unstructured Time for Activity?

Activity?

- [illegible] elements of "self" - [illegible] one's development years, personal survival was best achieved by stressing others at all costs, then practicing may be an established behavioral mode. These persons often believe that they can do nothing to help themselves and therefore their survival depends upon others; they often lose touch with their own needs and concentrate too hard on helping others.
- [illegible] elements of self and others - activity and coping may best be achieved if one's own and personal abilities to cope and reason are maximized. This skill is important for everyone but problems in communication among of self and others are for-gotten and one resorts to relying on only the facts involved in the situation. Instead of acknowledging own personal feelings, or commenting upon what one has heard from the other, facts be-lieved to be appropriate to the content of the situation are relied. No person-to-person connection has been established.
- [illegible] elements of self, other, and context) - all three of the essential elements of effective communication are obtained. Persons who use an interpersonal style of communication exhibit maximal diversity or accurately to what is said to them; internal responses are appropriate and off the point. Sometimes they attempt to laugh themselves. Meaningful contact with others is seldom established.

- Ask participants to create a brief role play or give an example from their actual family experience which will demon-strate/demonstrate each participant's personal discomfort points. Other examples from participants may be specific or non-specific as drawn from personal experience. Note the following examples which is

[illegible]

[illegible]

[illegible]

[illegible]
Time for
Activity[1]

Activity[1]

- Sometimes it may even be difficult to personally comment on the content in which one finds oneself. If an individual is part of a group whose exercise seems to understand and agree to what is going on, it is risky to acknowledge that one doesn't understand.

- Emphasize need to use previously discussed listening skills. Brainstorm handout "Ten Commandments for Good Listening" (see Examples from Exercise Training Experiences).

- Summarize the emergent communication style exposed. Principle Switch: respond to any questions or comments.

  - Awareness of own internal state,
  - Awareness of what others are experiencing, and
  - Awareness of the context in which the relationship is taking place.

(15-20 min.)

Discussion / Draft Essay

- Discuss the highly personal nature of death and the implications this has for those caring for the dying; the continuing tension of understanding of the meaning of death for oneself.[2]

  - Need to accept both the positive and negative feelings inherent in the relationship with patient/family; the range of emotions is a part of the human response to living or dying. Sometimes a person of non-dancing, integrate positive and negative feelings, and not respond with one emotion.

  - Need to recognize and accept personal limitations of both a physical and an emotional nature. Define the limits of personal openness to compose an intimate relationship with patients/families and build into personal views the necessary distance between personal world

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[1] Kerrison, S., "The Interacting Process", in Garfield, F. (ed.), Psychological Care of the Dying Patient, New York, McGraw-Hill, 1978, pp. 110-126.

(Estimated Time for Activity)	(Activity)
	and work world which enlists the assistance of multiple persons and/or activities. •• Need to establish and maintain an ethical attitude which places professional responsibility in perspective with own values.
	• Provide facilitation and support in discussion as required.
(30-35 Min.)	Exercise - Staff Stress
	• Request a volunteer from among participants.
	• Offer an opportunity for the volunteer to discuss a stressful event or stressful feeling which is unresolved and has come about through a relationship with a patient/family.
	• Permit the individual to recount the event and the associated stressful feelings. Throughout the individual's presentation model intervening behavior which may be supportive, summarizing, clarifying, questioning, highlighting, reflecting, interpreting, listening, etc., in an effort to reduce the stressful feelings being experienced by the speaker.
	• Request the speaker involved in the exercise to discuss present feelings with the group (i.e. has there been a lessening of the stressful feelings?). Have the individuals commented on various intervening (communicative) techniques employed by the trainer which were helpful?
	• Open the discussion up to the larger group to permit questions and comments about the exchange.
	• Conclude discussion with emphasis that an important deterrent to burnout and coping with stressful events and feelings is peer support; each individual has a responsibility first to self and then to team member, in attempting to discern emotional limits. Build in preventive intervention strategies (e.g. team sup-

(Estimated Time for Activity)	(Activity)
	port meetings); pointing out that stress-related behavior during a crisis in patient management only increases the anxiety of the care provider.
(10-20 Min.)	Concluding Comments and Discussion
	• Encourage participants not to become overwhelmed by all the communication issues and skills which have been and will be discussed. Discuss the stages of learning skills (see Examples From Hospice Training Experience) and assure participants that practicing skills, eliciting feedback about skills, and the conscious use of skills will lead to integration of skills and congruent behaviors into personal lifestyle.
	• Suggest one mechanism for internal feedback on skill development: use of a journal about personal interrelationships with patients, families or colleagues.
	◦◦ Provides valuable feedback about personal communication skills and interpersonal style, and
	◦◦ Offers insight into intrapersonal issues and behaviors (e.g. What triggers my guilt/anger/hate? How do I set myself up? Does one scenario repeatedly affect me adversely?)
	• Convey the importance of participants accepting "neurotic-type" behavior in the dying episode just as they accept it in the living episode.*
	◦◦ Reaffirm the need for patients/families to employ ego-coping mechanisms; coping with stress and conflict does not always occur in perfectly adaptive fashion.
	◦◦ Discourage staff expectations for perfection (from patients, families, selves) in dying; there is no perfection in living.

* Pattison, E., "The Living-Dying Process", in Garfield, C. (ed.), Psychosocial Care of the Dying Patient. New York, McGraw-Hill, 1978, pp. 133-168.

(Estimated Time for Activity)	(Activity)
	◦◦ Encourage participants to guide patients/families toward more rewarding modes of coping as they would advise friends, confront loved ones, or counsel an acquaintance; do not assume a corrective intervention is required for each interaction with patients/families.
(10-20 Min.)	Closing Remarks
	• Assign homework for following session.
	◦◦ Each participant is to select a "safe", real confrontation situation with an individual from his personal or work life. The confrontation may have already occurred or is only anticipated. The interaction, as it occurred or might occur, should be thought through. (State that what gets said in the "community" is confidential; things are dealt with in confidence.)
	◦◦ Each participant is to visualize his own anger; look at the image that is conjurred up by that emotion (e.g. exploding volcano). Each is to think also, about the kinds of issues which trigger that emotional response.
	• Confirm time and agenda for the next session (including the exploration of conflict and anger).
	• Move around the room asking how each participant is feeling at the moment. Interact with each as appropriate/required.
	• Solicit feedback from the group about the day's activities and outcomes.
	• Respond briefly to comments and questions and adjourn session with appreciation for participant involvement.

Session 10 Interpersonal Skill Building as a Member of the Respite Team

Purposes of the Session

- To facilitate the reexamination of interpersonal communication styles in light of the quality of interpersonal relationships on the team,
- To practice interpersonal communication skills (particularly confrontation), and
- To further delineate stress management issues for the team and reach agreement about strategies to be employed in mutually supported coping.

Participant Preparation

- Complete previous session's assignment (i.e. "visualize personal anger").
- Identify a conflict that involves another individual that participant has seriously/not so seriously considered confronting. Develop the confrontation scenario mentally.

Trainer Preparation

- Review sections of the series: Monograph 3, Chapter III; Monograph 3, Chapter VII; Monograph 6, Chapters IV, V.
- Review, if desired, the following major written resources:
  - Bionnan, J., "A Third-Party Consultation Model for Resolving Recurring Conflicts Collaboratively", The Journal of Applied Behavioral Science, 13:3, 1977, pp. 303-314.
  - Goode, G. et al., Human Relations Development: A Manual for Health Services, Boston, Allyn and Bacon, Inc., 1975.
  - Kain, R., "Toward Collaborative Health Practice: Teaching - Learning Teams", Journal of Allied Health, 6, 1977, pp. 29-34.
  - Kane, R., The Interprofessional Team as a Small Group", Social Work in Health Care, 1:1, Fall 1975, pp. 19-32.
  - Luft, J., "The Johari Window: A Graphic Model of Awareness in Interpersonal Relations", Porter, L. and Mill, C. (eds.),

Reading Book for Human Relations Training, Arlington, VA, NTL Institute, 1976 edition, pp. 13-14.

- Knowlton, C., Training Exercises to Improve Interpersonal Relations in Health Care Organizations, Greenvale, NY, Panel Publishers, 1977.
- Schein, E., "Communication Processes", in Process Consultation: Its Role in Organization Development, Reading, MA, Addison-Wesley Publishing Co., 1969, pp. 15-30.
- Shurtman, C., and Dunbel-Schetter, C., "Interpersonal Relationships and Cancer: A Theoretical Analysis", Journal of Social Issues, 35, 1979, pp. 120-155.

Estimated Time for Activity	Activity
(5-10 min.)	Opening Remarks

- Review briefly the previous session:
  - Endorse application of some skills in the development of interpersonal relationships beyond patient/staff relationship.
  - Stress importance of confrontation skill as a positive and necessary skill in communication.
- Review purpose, agenda, and expected outcomes of the day's session; request group agreement.
- Respond briefly to any comments and/or questions participants may have.

(15-25 min.)	Discussion

- Generate discussion of the varying types and quality of relationships which exist between other health professionals in the community and hospice staff and (when comfortable) between hospice staff persons (intra-organizationally). Focus on communication styles rather than personalities.
  - Positive relationships - identify the characteristics of these re-

(Estimated Time for Activity)	(Activity)
	lationships, and/or personal communication styles, which enable these relationships to be positive. Reinforce enabling communication skills as identified.
	○○ Negative relationships - identify the dysfunctional characteristics and/or personal communication styles within the relationships which preclude more positive interactions. Identify communication skill deficits as alluded to.
	• Facilitate discussion of skill development to enhance the development of positive interpersonal relationships to facilitate the provision of humanistic patient care. (Notion of hospice being systemic: the caring and respect that are conveyed to other care providers enable that same giving at the patient/family level).
	○○ Note changeable behaviors (self) - those behaviors which individuals commit to change within themselves; skill enhancement.
	○○ Note uncontrollable behaviors (others) - those behaviors beyond our control; others will not change by our will, they must commit to generating personal change.
(15-25 min.)	Exercise and Discussion
	• Review "pictures of anger" (previous session's assignment).
	○○ Move from participant to participant; request verbal "picture of anger" from each.
	○○ Offer feedback to each participant following presentation of anger picture; attempt to determine if each individual is pleased with how personal anger is demonstrated.
	• Offer rationale for exercise:
	○○ View anger to determine personal comfort with that picture.

(Estimated time for activity)

(Activity)

- Seek confirmation from others in the group that personal anger is demonstrated as described (Optional: if thought to be beneficial to individuals to facilitate learning more about their "anger behavior". Monitor manner feedback is conducted if option is exercised).
- Understand behavioral demonstration of anger to determine implications for constructive confrontation.

(85-60 Min.)

Presentation and Discussion

- Discuss the importance of understanding own anger in order to improve confrontation ability; anger is the result of conflict which precedes confrontation.
  - In conflict we confront, not to get even but to get closer; result a resolve to achieve satisfactory closure.
  - If anger escalates in confrontation we are not listening well enough; in conflict resolution, resolve the anger, not own exits.
  - Desired result, a strategy; release personal anger in a constructive fashion, and in exits act listen to what the other is saying.
- Present for discussion, the theoretical construct of the "continuum of conflict" (see Examples from Anagram Training Experiences).
  - Avoidance - have assessed the situation and chose not to deal with the consequences that confrontation would bring; this is not denial because a conscious decision has been made.
  - Diffusion - if too much anger is present, confrontation will not be constructive; commitment to deal with the feelings but not at the immediate moment, an out is off till feelings are more controlled.
  - Confrontation - when people avoid dealing it can be a win-lose situ-

Estimated Time for Activity

Activity

Even personal integrity may be viewed to be at stake.

- Discuss "confrontation" as an effective communication skill: assess congruity between communication mode and personal integrity. Three options:
  - Coercion - the old "win-lose" situation where even the winner is a loser; "winning" are antisocial.
  - Negotiation - each person gives a little to one can have it all so no compromise.
  - Collaboration - values or self preserved.

Confrontation Exercise

- Place "Change Process Checklist" on blackboard/flipchart in the front of the group (see Handout from Creative Problem Exercise).
- Explain purpose and review it in terms of exercise:
  - Stress the need to prepare for and anticipate all contingencies before they occur (what learning the new skill).
  - Explain each aspect of the checklist: help participants work through the change process (Checklist Handout); each participant demonstrating his/her plans of preparedness and personal readiness for the per-sonal confrontation scenario chosen.
  - Explain the role of anxiety in the ability to successfully con-front; encourage acceptance of the anxious rather than hoping to "overcome" it.
- Encourage volunteer from the group who "always would like to get his/her point across" (Most volunteer has been observed sometimes himself to behaviors more about the exercise

Optional
Time For
Activity

Activity

and the probable reaction the individual to be confronted will exhibit.

- Engage in a role play with the volunteer (Explain everyone has played with whom determines how stressful the confrontation progresses. Model practice confrontation skills; demonstrate how to reduce some forms of disruptive behavior, assist in helping move openly and honestly with individual, being firm in unacceptable issues, reduce distraction in communication, firm in acknowledging issues but permitting introduction of happiness, living further explanation of ideas, help understand issues of behavior and meaning, and develop ideas and thinking about the issue and the process.

- Process the activity briefly with the role players. Solicit feedback about reactions, process, and outcomes of confrontation for individual. Was the exercise useful? How?

- Solicit feedback from larger group.

  - What was observed?
  - What seemed effective/ineffective? What didn't work?
  - What could the confronter have done which didn't?
  - Identify some of the skills?
  - What were their personal reactions?

- Identify any misunderstandings about the confrontation demonstrated or confrontation skills in general. Be sure you provide for the opportunity for everyone who wishes to give all their input any that encouraged by a person, you have allowed yourself to be protected.

- Bring closure to the exercise by suggesting that some personality types are "[illegible]":

  - [illegible] - "overlooked" and "the [illegible]" which make decisions.
  - [illegible] - don't want to [illegible] with someone.
  - [illegible] - [illegible] will [illegible] and don't interact when confronted.

Estimated Time For Activity*

Activity*

- [illegible] : [illegible]
- [illegible] : [illegible]
- [illegible] : [illegible]

For these basic personality types, [illegible] as are applicable, in each case.

- [illegible]
- [illegible]
- [illegible]
- [illegible]

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Coping Remarks

- Emphasize the need to practice skills.
- Facilitate the group's evaluation of the session.
- Address the subject of the reluctance of "normal" receiving or humanistic persons care.
  - [illegible]
  - [illegible]
- Attempt with special personal remarks and well wishes.

[illegible]

[illegible]

[illegible] Examples of Commencement Language

[illegible]

Model "Time for a"

[illegible]

[illegible]

[illegible]

[illegible]

Model "Time for a"

[illegible]

[illegible]

Metaphorical Phrases "Time for a"

[illegible]

[illegible]

Metaphorical Phrases "Time for a"

[illegible]

[illegible]

[illegible] Energie Nordbeck on "Communication in Small Group Learning"

[illegible]

[redacted]

Clarity of Expression:

Many people find it difficult to say what they mean or to express what they feel. They often simply assume that the other person understands what they mean, even if they are careless or unclear in their speech. They seem to think that people should be able to read each other's minds: "If it is clear to me, it must be clear to you, also." This assumption is one of the most difficult barriers to successful human communication.

A person who can communicate his/her meaning effectively to others has a clear picture in his/her mind of what he/she is trying to express. At the same time he/she can clarify and elaborate what he/she says. He/she is receptive to the feedback that he/she gets and uses it to further guide his/her efforts at communication.

Coping With Angry Feelings:

A person's inability to deal with anger frequently results in communication breakdowns. Some people handle their anger by suppressing it, fearing that the other person would respond in kind. Such people tend to think that communicating an unfavorable emotion reaction will be divisive.

Expression of emotions is important to building good relationships with others. People need to express their feelings in such a manner that they influence, affirm, reshape, and change themselves and others. They need to learn to express angry feelings constructively rather than destructively. The following guidelines can be helpful.

1. Be aware of your emotions.
2. Admit your emotions. Do not ignore or deny them.
3. Own your emotions. Accept responsibility for what you do.
4. Investigate your emotions. Do not seek for a means of rebuttal to win an argument.
5. Report your emotions. Congruent communication means an accurate match between what you are saying and what you are experiencing.
6. Integrate your emotions with your intellect and your will. Allow yourself to learn and grow as a person.

Emotions cannot be repressed. They should be identified, observed, reported, and integrated. Then people can instinctively make the necessary adjustments in the light of their own ideas of growth. They can change and move on with life.

Self-Disclosure:

An individual cannot really communicate with another person or get to know that person unless he/she can engage in self-disclosure. A person's ability to engage in self-revelation is a symptom of a healthy personality.

"I have to be free and able to say my thoughts to you, to tell you about my judgments and values, to express to you my failures and shames, to share my triumphs, before I can really be sure what it is that I am and can become. I must be able to tell you who I am before I can know who I am. And I must know who I am before I can act truly, that is, in accordance with my true self."

The Five Levels of Interpersonal Communication-

Level 5 - Cliche Conversion

4 - Reporting the Facts About Others

3 - My Ideas and Judgments

2 - My Feelings and Emotions...Affective Level

1 - Personal Dialogue

Guidelines for Affective Communication-

1. Affective communication does not imply a judgment of the other.
2. Emotions are not moral (good or bad).
3. Emotions are integrated with the intellect and will.
4. In affective communication, emotions are "reported."
5. With rare exceptions, emotions are reported at the time that they are being experienced.

Benefits of Affective Communication-

1. A real and authentic relationship, an "encounter" of persons...leading to growth in my own sense of identity, and a deeper and more authentic knowledge of the other. It has become a psychological truism that I will understand only as much of myself as I have been willing to communicate to another.

2. Self-knowledge is the beginning of growth. Having understood myself because I have communicated myself, I will find my patterns of immaturity changing into patterns of maturity. As I allow my emotions to arise and be identified, I can observe patterns of emotional reactions, and then examine, judge them...and I will change.

3. It will evoke from others a responsive honesty and openness which is necessary if the relationship is to be interpersonal, mutual. If I want another to be honest and open, I first need to be honest and open with him/her.

Interpersonal Barriers to Communication-

Roleplay Messages. These roadblocks all take responsibility away from the other person and tend to put the person under external

control. Solution messages secretly say: "You're too dumb to figure out the problem, so I have to do it for you."

1. ORDERING, DIRECTING, COMMANDING. Telling the other person to do something...giving an order or command.

2. WARNING, ADMONISHING, THREATENING. Alluding to the use of your power by telling the other person what consequences will occur.

3. MORALIZING, PREACHING, OBLIGING. Telling another person what should or ought to be correct behavior.

4. ADVISING, GIVING SUGGESTIONS OR SOLUTIONS. Telling the other person how to solve his or her problems.

5. PERSUADING WITH LOGIC, ARGUING, INSTRUCTING, LECTURING. Trying to influence the other person with facts, counter-arguments, logic, information, or your own opinions.

Judgment Messages. These roadblocks diminish the self-worth and integrity of the other person, saying in effect: "There is something wrong (bad) about you that needs to be fixed."

6. JUDGING, CRITICIZING, DISAGREEING, BLAMING. Making negative judgments or evaluations of the other person.

7. PRAISING, AGREEING, EVALUATING POSITIVELY, APPROVING. Manipulating the other through flattery or implied promise of reward.

8. NAME-CALLING, RIDICULING, SHAMING. Making the other person appear foolish; stereotyping or categorizing the person in negative ways.

9. INTERPRETING, ANALYZING, DIAGNOSING. Analyzing the other's motives and behavior; communicating that you have the other person figured out or "diagnosed."

10. REASSURING, SYMPATHIZING, CONSOLING, SUPPORTING. Trying to make the other person feel better; talking the person out of strong feelings; trying to make the feelings go away; denying the strength of the feelings.

11. PROBING, QUESTIONING, INTERROGATING. Trying to find reasons, motives, causes; searching for more information to help you solve the problem.

Denial Messages.

12. WITHDRAWING, DIVERTING, MORALIZING. Trying to get the other person away from the problem; withdrawing from the problem yourself; distracting the person, kidding the person out of strong feelings; pushing the problem aside.

Listening Skills

1. ATTENTIVE - Passive listening with accompanying non-verbal behaviors (posture, eye contact, etc.) that communicate your interest and concern.

2. NON-COMMITTAL ACKNOWLEDGEMENT - Brief expressions that communicate your understanding, acceptance, and empathy such as:

"Uh"	"Really"
"I see"	"No Fooling"
"Mm-hmm"	"You did, huh"
"How about that"	"Interesting"

3. DOOR OPENERS - Invitations to expand or continue the expression of thoughts and feelings. Again, you are showing interest and concernment. Examples:
"Tell me about it"
"I'd like to hear your thinking"
"Would you like to talk about it?"
"Sounds like you've got some feeling about this"
"I'd be interested in what you've got to say"

4. CONCEPT PARAPHRASING - Putting the factual portion of the message into your own words and sending it back to check your accuracy in understanding. Examples are:
"So you really told your boss off"
"You're saying, if your plan works the problems will be solved"
"She just keeps going on and on, huh?"

5. ACTIVE LISTENING - Helping the sender to understand both the thoughts and feelings of his or her communication. You do this by feeding back the underlying feelings you hear as well as the content of the message. Examples are:
"You would upset when he uses your equipment"
"You are not pleased with the way the report is coming"
"You're pleased about what to do next"

Or by sharing an observation of the other's behavior to bring out feelings that are not being expressed verbally. Examples:
"You look sad"
"You seem anxious and upset"
"I think you're getting nervous about the late hour" (after noting clock gazing)

GOALS OF THESE SKILLS -

1. To demonstrate concern for and acceptance of the person experiencing a problem.
2. To indicate to the other person that he or she has been heard and understood and to give the other an opportunity to correct any inaccuracies in your understanding.
3. To give the other a chance to ventilate, to feel relieved, to release the grip of negative feelings.
4. To further responsibility in the other to do most of the problem defining and problem solving.
5. To further movement from superficial symptomatic problems to the basic underlying problems the other is experiencing.

Sending Skills

The purpose of the sending skills is to ensure that the feelings, thoughts and wishes of the sender are clearly expressed in a way that is most likely to lead to greater understanding and acceptance by the listener. There are five sending skills: to say emotions, be specific, speak from a personal point of view, state positive wants, and make a positive relationship statement.

1. Say personal emotions - Openly state the emotions or bodily feelings you are having, like, "I feel frustrated," or "I am feeling happy", or "My stomach is in a knot." Sometimes it may be hard to say what your emotions or feelings are. It is necessary then to say a little about that, which may also help you become clearer on what they are. When you do not say your feelings it is easy for the other person to misinterpret the meaning for you of what you are saying, or for you to not be clear about what you mean.

2. Be specific - Say in concrete terms the specific situation and behavior you are talking about. If you say something like, "I don't like how you have been treating me lately," the listener will not really know what it is you are talking about. Much more understandable is a specific statement like, "I was upset yesterday and I wanted to talk about it, but you kept telling me not to worry, which made me think you didn't want to listen to me."

3. Use a subjective, personal point of view - Say how you feel or think about something, not how something "actually" is "out there." Stating something subjectively means that you are aware you are talking about your perception or interpretation of the situation or of the other person, and that your perception or interpretation may not be completely accurate. You are more likely to avoid an argument by saying, "It seems to me that you are not doing your homework," than to say, "You are not doing your homework." This is most damaging when it takes the form of an accusation: "You are lazy," or "You are unfair" rather than "I don't see you doing any work around the house," or "I think you are not being fair to me." We are each the ultimate authority on how things look to us; an argument is therefore less likely when we clearly label what we say as our own experience and not as "fact."

4. Say a behavioral action want - This means to include in your message what you would specifically like the other person to do or say. It is again important here to be specific. Rather than saying "I want you to be more caring" which leaves the listener uncertain about what to do, say something like "I want you to hug me when I come home" or "I want you to ask how I am feeling when I act upset." It is especially important that action wants are couched with reasonable. This may serve a great deal of time and unnecessary argument. Since the other person may be willing to do what you want, though not agree with your negative opinion.

5. Make a positive relationship statement - Say something positive about the relationship, why it is important to you or why you like the other person. This will reassure the listener that the value of the relationship is buried by the particular issue at the moment.

small differences often consume a great deal of time while common wishes and interests go unsatisfied. A positive relationship statement helps to put negative feelings in perspective. Some examples of positive relationship statements are, "I think that one reason I am so upset when you don't listen is that your understanding is more important to me than anyone else's." or "I am glad you brought this problem up because our relationship means a lot to me and I want you to care about me," or "Even though I feel angry I also know that you have been trying hard and I really appreciate that." The point here is to be able to get past the particular issue to a positive sense of each other as valued persons.

GIVING FEEDBACK: A CHECK LIST

For each item listed below draw a circle around the number on each scale that best characterizes your feedback style. Comments elaborating on each item are helpful.

1. Judgmental Expression of Feeling. Not Describing your own emotional state, e.g., "You are a very cowardly person."	1 2 3 4 5	Direct Expression of Feeling. "Owning" your own feelings by describing your emotional state, e.g., "I like you very much."
2. Descriptive Feedback. Describing actions to behavior, e.g., "You are angry with me."	1 2 3 4 5	Descriptive Feedback. Observing and describing the behavior to which you are reacting, e.g., "You are frowning and your hands are clenched in a fist."
3. Evaluative Feedback. Passing judgment on another person's behavior or imposing "standards," e.g., "You shouldn't be so angry."	1 2 3 4 5	Nonevaluative Feedback. Commenting on behavioral evidence (seeing and hearing) rather than on motive, e.g., "Your anger is an appropriate a feeling as any other."
4. General Feedback. Giving broad appraisals and not indicating specific behaviors, e.g., "You're generally trying today."	1 2 3 4 5	Specific Feedback. Pointing out the specific actions to which you are responding, e.g. "When you finished, I felt annoyed."
5. Pressure to Change. Implying that people are not behaving according to your standards, e.g., "Don't you see 'Sonny'?"	1 2 3 4 5	Freedom to Choose to Change. Allowing others to decide whether they want to change their behavior, e.g., "Does you current be 'Sonny'? I hate put down."
6. Delayed Feedback. Withholding feedback to observe behavior until later, e.g., "I was really hurt yesterday when you ignored me."	1 2 3 4 5	Immediate Feedback. Responding immediately after the event, e.g., "I'm feeling hurt because you're not responding to me."
7. Personal Feedback. Focusing projection on people outside the group, e.g., "My friends and me we are being very aggressive."	1 2 3 4 5	Group-Shared Feedback. Focusing attention on events that occur in the group, e.g., "Does this group and me we are being very aggressive?"

(iii) Example of a Homework Assignment

[illegible]

[illegible]

[illegible]	[illegible]
1.	1.
2.	2.
3.	3.
4.	4.
5.	5.

[illegible]

[illegible]

[illegible]

[illegible]

[illegible]

* * * * * *

[illegible]

5.2 [illegible]

[illegible]

[illegible]

(h) Example of Skills Integration Chart

In Session 9 one trainer began to sense from participants a feeling of being overwhelmed. Many issues had been identified and skills introduced in discussions of behavior which fostered the development of positive interrelationships. Reassurance from the trainer eased many of these feelings as it was acknowledged that skills integration is a process which occurs over a period of time with investment from those acquiring the skills. The following illustration was presented to depict the stages of learning.

Stages of Learning Interpersonal Skills

#1
Guilty
Feeling inadequate in communication; lacking in, or unaware of, skills.
#2
Phony
Practicing of skills goes on but it seems so structured, conditioned, and phony.
#3
Awkward
Skills have been "learned" but individual still feels unnatural or awkward in utilizing them; not spontaneous.
#4
Skillful
Prepared. but skills haven't been integrated into lifestyle. Question at this juncture - Does how I live contribute to my philosophy?
#5
Lifestyle
Integration achieved.

(i) Example of Comments From Discussion on Staff/Staff and Health Professionals/Staff Relationships

In a discussion of the relationships participants foster among themselves and with other health and social service professionals in the community, the importance of recognizing personal motivation for caring for the dying was explored. The interpersonal relationships between staff were identified as markers of any problems in the environment which may potentially present blockage to the effective provision of humanistic patient care. Several repetitive problematic communication issues were disclosed. In Session 10 these problems served as useful examples for a discussion of confrontation. Following are some of the comments (not verbatim) made by either trainer or participants.

> It seems to me that hospices are typically staffed with persons who have received their formal training and a collection of acquired experiences from conventional care settings. In many instances even those persons who may be familiar with the interdisciplinary, or more likely, the multidisciplinary team approach, have gained that familiarity from an hierarchial team experience. Team members may have difficulties in either assuming or relinquishing leadership responsibilities. Conflict may arise between individuals as a consequence of differences in leadership roles and leadership styles.

* * * * *

> "My patient" references by an individual who has been providing a great deal of care to one patient is harmful for the sense of "team". When one team member has been singled out by a patient as a "confidant" it can be very ego-invigorating for that person but potentially dysfunctional for the team if the individual continues to view the patient as his own solely. We need to provide honest, timely feedback to the team member about how that makes us feel.

* * * * *

> I can see how our environment here affects the emotional well being of each of us. It permits us to go into homes and provide more humanistic care.

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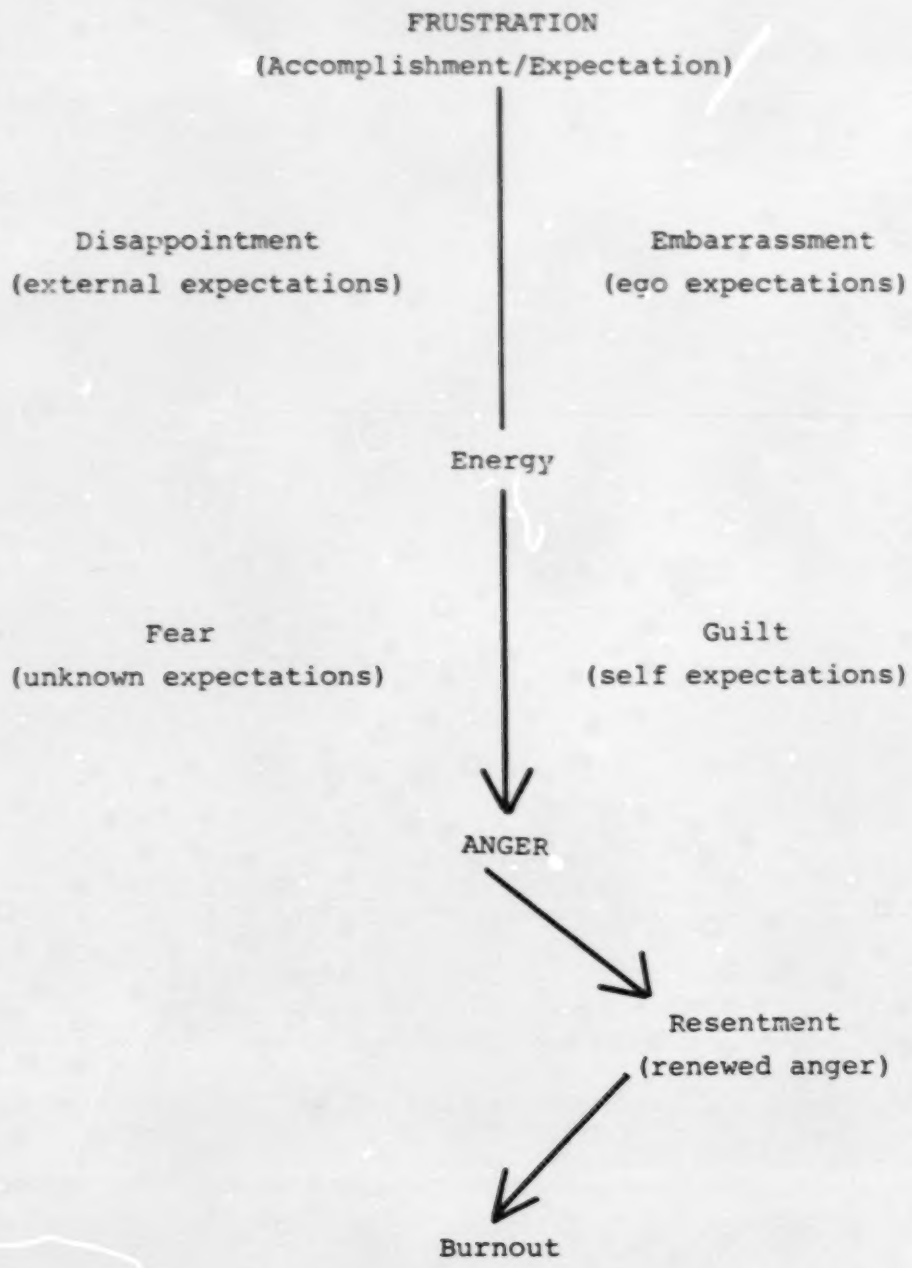
There may be the tendency, unwittingly, to become covetess of the hospice patient, inadvertently wanting to become the answer to all his/her dilemmas. With a goal to provide the most humanistic patient care, hospice staff must be unselfish helpers, recognizing that when specialized services are needed that aren't provided by the hospice, the appropriate resources within the community will be identified and contacts made. It is the responsibility of each of you to provide the most responsive, humanistic care to the patient. That means each of you should continually develop relationships with other professional health care providers and agencies within this community. The nurturance of ongoing relationships with diverse community resources not only establishes the likelihood for a timely response to patient/family needs when community resources are called upon, but may also provide the programmatic response, through education, to getting other provider agencies "on board" philosophically so that a crash course in what hospice is all about is not necessary each time services are required. The ongoing dialogue with other provider agencies may diminish feelings of competitiveness and foster acceptance at several levels.

(j) Example of "Anger is a Chosen Position" Chart

In Session 10 the trainer found it useful to use the following graphic demonstration (Exhibit 57) of a brief presentation on feelings which underlie "anger".

EXHIBIT 57

Anger is a Chosen Position



(k) Example From Confrontation Exercise

The following checklist was suggested by one trainer as a helpful self-exercise to determine state of preparedness when a difficult confrontation is anticipated. In concert with a confrontation exercise, the trainer assisted a role play volunteer in clarifying some issues associated with her feelings about the impending confrontation.

Change Process Checklist

Experimentation - role play the confrontation with self so that the blueprint is imprinted. Will the confrontation be successful?

Risk - what stands to be lost by confronting? Visualize the worst possible outcome; is this a likely fantasy? Can you accept the risks?

Insecure/Secure - how emotionally prepared are you to confront? What would make you feel more secure? (Insecure = 0, Secure = 10; on a scale of 1-10, security level should be 6 or 7).

Fear - identify the fear; work it through (get support from others to assist in realizing and confronting that fear).

Challenge/Payoff - what is gained by the confrontation; is it a moral/emotional/financial/material victory? Is the challenge internal or external (for self or others?); does this make a difference? Are the risks worth the payoff?

Courage - how realistically are you considering confrontation? Are you 85-90% prepared to confront? Would this confrontation be more successful if postponed temporarily?

4. SELECTED RESOURCE MATERIALS FOR TRAINING: COMMUNICATION SKILLS AND STYLES; PATIENT/STAFF RELATIONSHIPS, STAFF/STAFF RELATIONSHIPS, AND OTHER HEALTH PROFESSIONALS/STAFF RELATIONSHIPS

The following references represent selected resources for use by trainers and participants to supplement the content contained in Sessions 8, 9 and 10. As may be expected, many of the citations are not hospice specific; they represent a collection of articles, books and training publications which explore interpersonal communication theory and the related experiential dynamics. Some of the literature probes interpersonal issues which have relevant implications for personal communication styles and stress management practices. It is not suggested that the list is exhaustive; it will provide a valuable starting point for a more indepth examination of training issues by either trainer or participant.

The citations below represent a range of topics under the rather broad heading of communication and interpersonal relationships, indicative of the content dealt with in this chapter. They appear alphabetically listed by senior author and when an item has particular relevance to one or more specifically identified issues, it is parenthetically coded at the conclusion of the citation. Communication issues and applications are included in this coding as they relate to the following:

(1) = Interpersonal Skill Building
(2) = Patient/Staff Relationships
(3) = Staff/Staff Relationships
(4) = Stress Management

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E. MONITORING OF HUMANISTIC PATIENT CARE PROVISION

Training in humanistic patient care, just as any type of training, requires continual reinforcement and monitoring; a self-renewal mechanism which encourages that what transpired in training is not lost to the everyday routines of the individuals who participate in training. Each trainer has monitoring responsibilities during formal training, but hospice staff have responsibilities both to themselves and to one another, for the ongoing assessment and maintenance of humanistic patient care. It is necessary that hospice staff and administration recognize the importance of this monitoring.

- Trainer monitoring during formal training. At the conclusion of each session trainers are to facilitate an evaluation of the session (i.e., content and methodology). This is a vitally important step in the training process that must be actualized. It affords trainers and participants a mutual opportunity to change the course of training if participants' needs are not being addressed.

- Staff ongoing monitoring. At the conclusion of "formal" training it becomes the responsibility of training participants to continually self-assess their effectiveness in achieving their goal to delivering humanistic patient care. Opportunities for structured monitoring and self-renewal must be adhered to to facilitate the integration of skills and processes learned.

Recognizing that the trainer (probably) will not be available to the hospice staff as frequently as monitoring activities necessitate, the trainer should assist training participants and hospice administration in formulating thoughts about some specifics of ongoing monitoring well in advance of final separation from participants. The following suggestions are made to facilitate the transition from trainer monitoring activities to staff ongoing monitoring.

- Facilitate evaluation of each session; reaffirm the importance of intent of this activity (i.e., participant feedback influences the nature of subsequent sessions).

- Encourage participants to practice skills with one another in diads or triads.

- Emphasize continually the necessity for ongoing self-renewal activity.

- Explore options for structured monitoring activities in times most adaptable/amenable to hospice

staff's own schedules and time constraints (e.g., 30 minutes every third team conference, one inservice session per quarter).

- Facilitate the scheduling of the first meeting for self-renewal past "formal" training.
- Create a "priority list" of issues to be worked on in ongoing monitoring activities (may be done in 15 minutes during the closing of the "formal" training session).
- Develop a schedule for monitoring activities; obtain commitments from all.
- Devise a strategy (model) for dealing with identified priorities.
- Facilitate discussion to determine if and how patients/families could appropriately be used to monitor the provision of humanistic patient care. Carefully explore all related issues (e.g., What would we want to know from them? How would we get the information? Could this same information be obtained elsewhere?)

The importance and inherent benefits of ongoing monitoring cannot be emphasized enough by the trainers. Exhibit 58 following, offers one simple model of how hospice staff could assess their own activities in the provision of humanistic patient care.

Exhibit 58

A Model for Ongoing Self-Monitoring

- Identify, through group process, the following:
  - the "generating" forces enabling the provision of humanistic patient care (i.e., behaviors, norms, environment; not individuals),
  - the "stiffling" forces compromising the provision of humanistic patient care (i.e., behaviors, lack of skills, norms; not individuals).
- Create a priority list of issues (areas for improvement) to be worked on in self-renewal sessions.
- Assign each individual one of the identified areas; individual must propose a solution and return to the group at a scheduled time to present the proposed solution for discussion.
- Develop a schedule for monitoring; identify issues to be discussed and the individual who is to facilitate the discussion.
- Develop the "ground rules" for meetings and make all participants aware of them.
- Maintain a task-oriented profile but permit sufficient flexibility to respond to "new" priority issues as they develop.
- Conclude each monitoring session with an evaluation of the activity. A reassessment of priority issues, and a confirmation of the next meeting (issue and facilitator).

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APPENDIX

A. Definitions

B. Contributors to the Series

C. Table of Contents of Five Monographs

APPENDIX A

DEFINITIONS

Meeting the needs of terminally ill patients and their families requires an interdisciplinary and humanistic approach to care. "Meeting needs" infers that the patients and families communicate their needs, directly or indirectly, and that the staff members understand the communication. Staff members also independently recognize patient and family needs and can help them to acknowledge unrecognized yet real needs. The staff then makes every effort to find approaches to meeting the needs.

The patient is recognized as a person with decision making, planning, care delivering and evaluating powers. The family is viewed in the same way. Both patient and family understand their rights and realize that they are in control. They also recognize that they are capable of personal growth through the dying experience. Humanistic patient care is this approach by staff to patients and families. It includes state-of-the-art professional physical care and psychosocial and spiritual support of patients and families as they maintain their independence and their preferred way of life and death.

As the needs of terminally ill patients and their families may be in multiple areas, multiple skills and disciplines must be utilized in any attempt to meet them. The approach, then, must be multidisciplinary. As these needs overlap for the patients and families, and as the solutions to some needs may conflict with solutions to other needs of the same patient and/or family, an interdisciplinary approach is needed. As no one person or profession can meet all the needs, and as no one person can successfully cope alone with the stresses inherent in this work, a team approach is indicated. The patient and family participate as team members. An interdisciplinary team, providing input into assessment, decision making, care and evaluation, with blurring of traditional roles and mutual information sharing and support, has been found to be a most effective approach to terminal care.

1. Interdisciplinary Team

   Team activity is not confined to health care nor to any one specific structure. There are board member teams and management teams as well as staff teams. Teams may have consistent membership or may have rotating members; team members may work together with frequent team meetings, or they may seldom meet face to face. Teams may be made up of members of one profession or discipline, or may include more than one profession or a mixture of professions and disciplines. An interdisciplinary team

has been defined by Ducanis and Golin* as "a functioning unit, composed of individuals with varied and specialized training, who coordinate their activities to provide services to a client or group of clients". Rubin, Plovnick and Fry** add that coordinating activities requires teamwork. "This need for coordination and working together is called 'interdependence'. Any job that cannot be done by just one person requires some degree of interdependence," (Hospice interdisciplinary teams are discussed at greater length in Monographs 1 and 2.) The Health Resources Administration has defined an interdisciplinary health team as follows:

> INTERDISCIPLINARY HEALTH TEAM is composed of three or more health professionals, including physicians and physician's assistants or nurses, who relate on an equal non-hierarchial basis to each other in the provision of health services to primary, secondary and tertiary care patients. Usually such teams have received didactic and experiential training concerning the roles of other health professionals, interpersonal communications, small group process, other organizational development concepts, and patient/provider relationships. The patient and the patient's family are considered members of the interdisciplinary health team, along with the physician and such staff as physician's assistants, pharmacists, clergy, social workers, psychologists, administrators and volunteers as appropriate.***

2. Humanistic Care

Humanistic patient care is a term used to describe an activity that evades clear definition. In hospice, it has been defined as a timely comfort-oriented focus for patient care and

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* Ducanis, A. J. and Golin, A. K., The Interdisciplinary Health Care Team, Germantown, Maryland, Aspen Systems Corporation, 1979, page 3.

** Rubin, I. M., Plovnick, M. S., Fry, R. E., Improving the Coordination of Care: A Program for Health Team Development, Cambridge, MA, Ballinger Publishing Co., 1975, page 3.

*** Adapted from: A Discursive Dictionary of Health Care, U.S. House of Representatives, Subcommittee on Health and Environment, 1976.

family care delivery. It indicates an increased emphasis on the non-scientific elements of professional patient care (without reducing emphasis on the scientific elements).

The Health Resources Administration has defined humanistic patient care by reference to a definition of humanistic medicine:

> HUMANISTIC MEDICINE is medical practice and culture which respects and incorporates the concepts that: the patient is more than his disease, the professional more than a scientifically trained mind using technical skills, both are whole human beings interacting in the healing effort, a person is more than his body, he is a unique, interdependent relationship of body, mind, emotions, culture and spirit; each person has the capacity to define and be increasingly responsible for himself, the professional seeks to assist the patient in taking and fulfilling his responsibility for himself; health and disease are not matters of the moment but have intricate past, present and future; disease, physical, emotional or spiritual pain and suffering, aging and death are meaningful events in an individual's life; and effective health care requires not just conventional skills but also effective development and use of human qualities such as intuition, inventiveness, and sympathy.*

3. Other Definitions

Operative definitions of other terms used in the monographs are provided to ensure clarity of content:

> ORGANIZATION DEVELOPMENT (O.D.) means "an evolving collection of philosophies, concepts, and techniques, which aims at the improvement of organization performance by intervening in social systems (the patterns of social relations existing within a formal organization). Attempted changes may be directed at individuals, dyads, groups, intergroups, formal structures, or cultures. O.D. is not yet a coherent applied science. It derives more from the social than the biological

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* Adapted from: A Discursive Dictionary of Health Care, U.S. House of Representatives, Subcommittee on Health and Environment, 1976.

or physical sciences."*

FACILITATION/FACILITATOR. The verb to facilitate refers "to a process by which events are 'helped to happen'. Facilitating is a kind of influence role which is neither authoritarian, on the one hand, nor abdicative, on the other."**

TRAINER in this series of monographs means the formal leader of the training program sessions, as well as the person conducting the data collection, data analysis, and training program design. This term is used throughout, even though this person is facilitating staff development rather than teaching technical knowledge and skills. As it is recommended that this person be found outside the hospice setting, the person is acting as a consultant to the hospice. The term trainer is used here, therefore, in lieu of the terms consultant, facilitator, process person, change agent, O.D. specialist, or leader.

EXPERIENTIAL AND AFFECTIVE LEARNING. Experiential learning means learning through experiencing within the group, and then analyzing and generalizing from the experience. The experience may be actual or simulated (through role playing, or through video taping of group members' interactions). It refers to experiences presently taking place within the group members (not reporting of experiences that have taken place with others). Affective learning implies emotional learning (as in the heightening of awareness) rather than cognitive learning, and includes exploring and generalizing feelings. It may refer to either individual or group learning.

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* Vaill, P. B., "An Informal Glossary of Terms and Phrases in Organization Development", in Jones, J. E. and Pfeiffer, J. W. (editors), The 1973 Annual Handbook for Group Facilitators, La Jolla, CA, University Associates, 1973, reprinted with permission in Weisbord, M. R., Organizational Diagnosis, A Workbook of Theory and Practice, Reading, MA, Addison-Wesley Publishing Company, 1978, page 75.

** ibid, page 73.

APPENDIX B

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